AD_____

Award Number: DAMD17-01-1-0026

TITLE: Living with Early Prostate Cancer: Decisions and Outcomes

PRINCIPAL INVESTIGATOR: Jack A. Clark, Ph.D.

CONTRACTING ORGANIZATION: Boston University
Boston, MA 02118

REPORT DATE: August 2005

TYPE OF REPORT: Final



PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;
Distribution Unlimited

The views, opinions and/or findings contained in this report are those of the author(s) and should not be construed as an official Department of the Army position, policy or decision unless so designated by other documentation.

# REPORT DOCUMENTATION PAGE

*Form Approved*
*OMB No. 0704-0188*



| 1. REPORT DATE | 2. REPORT TYPE | 3. DATES COVERED |
|---|---|---|
| 01-08-2005 | Final | 9 Jul 2001 – 8 Jul 2005 |

**4. TITLE AND SUBTITLE**

Living with Early Prostate Cancer: Decisions and Outcomes

**5a. CONTRACT NUMBER**

**5b. GRANT NUMBER**
DAMD17-01-1-0026

**5c. PROGRAM ELEMENT NUMBER**

**6. AUTHOR(S)**

Jack A. Clark, Ph.D.

**5d. PROJECT NUMBER**

**5e. TASK NUMBER**

**5f. WORK UNIT NUMBER**

**7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)**

Boston University
Boston, MA 02118

**8. PERFORMING ORGANIZATION REPORT NUMBER**

**9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES)**
U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

**10. SPONSOR/MONITOR'S ACRONYM(S)**

**11. SPONSOR/MONITOR'S REPORT NUMBER(S)**

**12. DISTRIBUTION / AVAILABILITY STATEMENT**
Approved for Public Release; Distribution Unlimited

**13. SUPPLEMENTARY NOTES**

**14. ABSTRACT**

To examine men's perceptions of life transitions associated with prostate cancer through an analysis of their narratives, obtained in in-depth, qualitative interviews; compare men's narratives of perceived transitions with respect to quality of life outcome states, i.e., good vs. poor prostate cancer-related quality of life. Phase 1: interview participants in our quality of life survey of previously treated patients, stratified by quality of life. Phase 2: interview members of our prospective cohort who have completed 36-month follow-up, stratified by quality of life states and observed changes in urinary, bowel, and sexual function. Phase 3: prospectively interview patients with new diagnoses of early prostate cancer prior to treatment and 12 months later. Comparative analyses, with comparisons between strata and the three cohorts, have characterized the structure and content of patients' narratives of prostate cancer, including specific changes in identity and interpersonal relationships, that are linked to quality of life outcomes.

**15. SUBJECT TERMS**
prostate cancer, quality of life, patient narratives

| 16. SECURITY CLASSIFICATION OF: | | | 17. LIMITATION OF ABSTRACT | 18. NUMBER OF PAGES | 19a. NAME OF RESPONSIBLE PERSON |
|---|---|---|---|---|---|
| a. REPORT | b. ABSTRACT | c. THIS PAGE | | | 19b. TELEPHONE NUMBER *(include area code)* |
| U | U | U | UU | 103 | |

Table of Contents

## INTRODUCTION

An estimated 210,000 American men, mostly aged 50 and older, will be told by their doctors that they have early prostate cancer in 2005. For many, if not all, this news will precipitate a crisis. They will be confronted with an ominous diagnosis and asked to make choices between a growing number of therapeutic alternatives (radical prostatectomy, external beam radiotherapy, brachytherapy, cryosurgery, observation/expectant management) in a context of uncertainty. While none of the active treatment alternatives has been shown to offer an efficacy advantage over observation, each is associated with long-term urinary, bowel, and sexual complications, which may have substantial effects on quality of life. Most of these men will survive for many years, some living with problematic treatment-related physical changes, psychosocial changes, and the possibility that treatment did not eliminate prostate cancer as a serious threat. The growing appreciation of the salience and magnitude of these effects, for both individual patients and an aging population, has resulted in advances in our knowledge of quality of life outcomes, informed by improved methods for measuring prostate cancer-related quality of life. Yet, our understanding of how men respond cognitively and emotionally to the diagnosis of prostate cancer and its treatment remains limited. In particular, we lack information about how men perceive the changes they go through, from their pre-treatment state to their health and quality of life state after treatment.

However, advances in social and behavioral science methods for studying how people perceive and make sense of their own lives through personal narratives offer a productive approach for research on the changes in quality of life that may be occasioned by the diagnosis and treatment for early prostate cancer. Narratives have clearly identifiable grammatical structures. They can be rigorously analyzed as meaningful social objects. Moreover, there is growing interest in patients' narratives of their illnesses within the medical community. Clinicians and researchers are regaining an appreciation for patients' stories, an interest as ancient as Hippocrates, since the stories individuals tell about themselves when ill reveal the ways in which they understand their illnesses and the impacts of illness on their lives.

Our study extends a productive line of research on men's perceptions of the physical and psychosocial impacts of prostate cancer. We have developed questionnaires, research designs, and substantial databases for studying men's perceptions of the physical complications of treatment for early prostate cancer and the psychosocial impacts of these complications, as well as the emotional, symbolic effect of a cancer diagnosis. Much of this work has been strongly informed by what men say in open-ended discussions of their experiences, such as focus groups. Often, when asked to describe in their own words the impact of prostate cancer, men will begin by saying something like, "Well, it's a long story."

In this study, we have built on our previous research, particularly our well developed quantitative databases, to collect and analyze systematically men's narratives of prostate cancer, and examine their relationship with physical and psychosocial outcomes of care. We have proceed in three phases. First, we identified men who completed psychosocial questionnaires in our recent survey of quality of life outcomes, and who fall into one of several contrasting outcome groups, that is, good or poor quality of life. We interviewed these men, all of whom were diagnosed 12 to 48 months previously, elicited their narratives, and compared the stories associated with either good or poor quality of life. Second, we verified the findings of the first

phase by replicating the analysis among men who participated in a long-term follow-up study of physical complications of treatment. Thus, we will also examine the association between men's stories and carefully observed physical changes in urinary, bowel, and sexual function. Third, we directly examined developing stories of the impact of prostate cancer by prospectively interviewing a small group of newly diagnosed men at two points in their prostate cancer "careers," shortly after diagnosis and 12 months later.

## BODY

### Accomplishment of Planned Tasks

Task 1: Characterize men's retrospective perceptions of life transitions associated with early prostate cancer in a sample of previously treated patients.

a. Identify subsample of 40 respondents to prostate cancer quality of life survey, defined by quality of life outcome status
b. Conduct in-depth interviews with subsample of respondents.
c. Analyze men's narratives of their lives with early prostate cancer.

A total of 24 patients who participated in the previous (1999), VA HSR&D-funded quality of life survey were successfully interviewed in accomplishing Task 1. Others who we attempted to contact and interview were either lost to follow-up (no longer at last known address; unable to locate) or declined our invitation to participate in an interview. Combined with 26 subjects interviewed from that survey panel prior to the initiation of this project, we have produced a very large database of 50 in-depth, qualitative interviews with patients previously treated for early prostate cancer.

All completed interviews were transcribed and entered into the qualitative database. We have constructed a data dictionary that represents the major topics pertaining to the experiences of diagnosis, treatment decision making, and quality of life outcomes of treatment for early prostate cancer. All interviews have been coded according to this dictionary.

**Table 1. Characteristics of Interview Respondents Selected from VA Survey Participant Cohort**

| | number of respondents |
|---|---|
| Site: | |
| Greater Boston, MA (Harvard Vanguard Medical Associates) | 25 |
| Buffalo, NY (VAMC) | 11 |
| Washington, DC (VAMC) | 14 |
| Age Group: | |
| 40 – 59 | 5 |
| 60 – 69 | 17 |
| 70 – 79 | 27 |
| 80 + | 1 |
| Marital Status: | |
| married | 28 |
| divorced/separated | 11 |
| widowed | 5 |
| never married | 6 |

| Table 1. Characteristics of Interview Respondents Selected from VA Survey Participant Cohort | number of respondents |
|---|---|
| Treatment for Prostate Cancer | |
| radical prostatectomy | 16 |
| external beam radiation | 21 |
| brachytherapy | 3 |
| hormone ablation | 2 |
| observation/watch and wait | 5 |

Task 2: Characterize men's retrospective perceptions of life transitions associated with early prostate cancer in a cohort of patients in which urinary, bowel, and sexual function have been monitored from pre-treatment baseline to 36 months post-treatment.

a. Administer survey, using patient-centered quality of life measures, to members of prospective cohort.
b. Identify subsample of 40 respondents to quality of life survey, defined by changes, from pre-treatment status, in urinary, bowel, and sexual function, and by quality of life status.
c. Conduct in-depth interviews with subsample of respondents.
d. Analyze men's narratives of their lives with early prostate cancer.

A survey instrument, based on the instrument developed in our previous survey of prostate cancer patients, was developed and sent to members of the cohort who had completed 36 months of follow-up in the Talcott/Clark prospective survey of urinary, bowel, and sexual function following treatment for early prostate cancer.[1] A copy of this questionnaire is appended. Eligible patients had valid baseline and 36 month data. Interim data, collected at 3, 12, and 24 months after the initiation of treatment or indication of a choice to pursue a "watch and wait" treatment approach, were also largely complete, but completion of interim data was not required for inclusion in Task 2. Of 338 names received from Talcott, 43 were excluded because of lack of valid baseline data; 19 were excluded because of lack of valid address; and 7 were deceased. The remaining 269 were sent questionnaires: ten actively refused and 24 declined to respond. Responses were obtained from 235 of 269: a response rate of 87.3%.

As planned, the survey data provided an opportunity to verify previous psychometric findings regarding psychosocial dimensions of prostate cancer-related quality of life. Psychometric analyses confirmed 11 previously defined quality of life scales, plus one new scale to assess the behavioral consequences of treatment-related bowel dysfunction.

Two of these scales were used to define four contrasting outcome groups for follow-up interviews: perceived cancer control and perceived quality of decision making. The former is assesses confidence in cancer control and related distress about possible progression. The latter assesses perceptions of having made a well informed decision in choosing a course of treatment. Together, they represent perceptions of the overall effectiveness of cancer treatment. These two scales were relatively unrelated (r=.28). Groups were defined according to median splits on these two dimensions, allowing classification of 225 of 235 subjects with sufficient data on the two scales.

Quality of life characteristics of the four groups are summarized in Table 2. In order to provide optimum contrast groups for the qualitative analyses of Task 2, we have sampled patients in maximally different Groups 1 (poor (-) control, poor (-) decision) and 4 (good (+) control,

good (+) decision). Interviews elicit narrative accounts leading to good and poor quality of life conclusions.

**Table 2: Characterization of Four Outcome Groups**

| All values are means, unless noted as % | 1 - control - decision | 2 - control + decision | 3 + control - decision | 4 + control + decision | p |
|---|---|---|---|---|---|
| Number of Subjects | 66 | 47 | 48 | 64 | |
| Age at Diagnosis | 66 | 63 | 65 | 63 | .035 |
| Physical Component Summary: SF-12 | 46 | 48 | 46 | 50 | .044 |
| Mental Component Summary: SF-12 | 49 | 53 | 53 | 54 | .005 |
| % Surgery | 23 | 38 | 43 | 37 | .001 |
| % External Beam Radiation | 65 | 36 | 39 | 29 | |
| % Brachytherapy | 11 | 22 | 7 | 29 | |
| % Observation | 2 | 4 | 11 | 5 | |
| Urinary Incontinence | 14 | 14 | 16 | 15 | .901 |
| %Urinary Incontinence worse since pre-treatment | 24 | 32 | 32 | 32 | .727 |
| Urinary Obstruction/Irritation | 23 | 18 | 22 | 19 | .190 |
| EPIC Urinary Bother | 17 | 11 | 15 | 12 | .199 |
| Bowel Dysfunction | 11 | 7 | 8 | 5 | .024 |
| %Bowel Dysfunction worse since pre-treatment | 25 | 22 | 17 | 13 | .431 |
| EPIC Bowel Bother | 14 | 8 | 10 | 5 | .012 |
| Sexual Dysfunction | 82 | 58 | 78 | 63 | <.001 |
| %Sexual Dysfunction worse since pre-treatment | 47 | 54 | 60 | 57 | .518 |
| EPIC Sexual Bother | 55 | 43 | 54 | 42 | .088 |
| Urinary Control | 90 | 95 | 92 | 95 | .107 |
| Bowel Control | 89 | 91 | 92 | 96 | .173 |
| Sexual Intimacy | 60 | 68 | 65 | 72 | .093 |
| Sexual Confidence | 27 | 47 | 33 | 45 | <.001 |
| Masculine Self Esteem | 80 | 87 | 86 | 89 | .003 |
| Health Worry | 28 | 20 | 9 | 11 | <.001 |
| PSA Concern | 62 | 75 | 68 | 65 | .150 |
| MOS Marital Function | 74 | 86 | 82 | 84 | .002 |
| Spouse Affection | 83 | 93 | 92 | 92 | .008 |
| % Regretful | 14 | 4 | 10 | 0 | .015 |
| Outlook | 39 | 47 | 46 | 48 | .401 |
| PSA Failure (≥ 1.0 or rose or rising) (%) | 70 | 57 | 27 | 38 | <.001 |
| Social Support | 60 | 84 | 66 | 83 | <.001 |
| Marital Status (%) | | | | | |
| married | 76 | 89 | 74 | 91 | .090 |
| widowed | 15 | 6 | 9 | 6 | |
| divorced | 5 | 4 | 13 | 3 | |
| never married | 5 | 0 | 4 | 0 | |

We interviewed 25 patients in completing Task 2. Additional interviews were unsuccessfully sought from 34 respondents, including 22 who could not be reached, 1 who died shortly after completing the quality of life survey, and 11 who declined to participate in an interview. While the number of participants is substantially less than the accrual goal, the 25 interviews comprise an adequate database for analysis. All four of the planned strata are represented. However, analysis of the survey data led us to redefine the two key scales—

Perceived Control of Cancer and Perceived Quality of Treatment Decision—in a more informative trichotomy, as demonstrated below in the discussion of the findings from the "Survey of Survivor Cohort."

All of these interviews were transcribed, entered into a comprehensive data base, and coded according to the dictionary developed in accomplishing Task 1. This enabled systematic comparisons of men's accounts by cohort, that is, comparisons between relatively short term (1-4 years) survivors in the first cohort and relatively long term (5-8 years) survivors in the second (Talcott) cohort.

| **Table 3. Characteristics of Interview Respondents Selected from Talcott Prospective Cohort** | **number of respondents** |
|---|---|
| Age Group: | |
| 40 – 59 | 5 |
| 60 – 69 | 15 |
| 70 – 79 | 5 |
| Marital Status: | |
| married | 22 |
| not married | 3 |
| Education: | |
| less than college degree | 12 |
| college degree | 13 |
| Treatment for Prostate Cancer | |
| radical prostatectomy | 8 |
| external beam radiation | 10 |
| brachytherapy | 8 |
| observation/watch and wait | 2 |
| Years since Treatment | |
| 4 | 8 |
| 5 | 6 |
| 6 | 3 |
| > 6 | 6 |
| Evidence of PSA failure | 10 |
| Perceived Control of Prostate Cancer | |
| low | 4 |
| moderate | 3 |
| high | 18 |
| Perceived Quality of Treatment Decision | |
| low | 4 |
| moderate | 6 |
| high | 15 |

Task 3:Characterize men's prospective perceptions of life transitions associated with early prostate cancer in a cohort of patients observed prior to treatment and 12 months following the initiation of treatment.

a. Identify and recruit cohort of 40 patients with newly diagnosed early prostate cancer at two sites: VAMCs at Buffalo, NY and Washington, DC.
b. Conduct baseline, in-depth interviews
c. Conduct 12-month follow-up interviews.
d. Analyze men's narratives of their lives with early prostate cancer.

As indicated in the 2003 annual report, the Washington, DC site was replaced by Boston Medical Center, Department of Urology. Administrative problems at Washington, DC VAMC entirely precluded efficient implementation of the project at that site. The change in protocol was approve by the Boston University Medical Center Institutional Review Board on 22 January 2003.

We completed baseline and 12 month follow up interviews with 32 patients with newly diagnosed early prostate cancer. In addition, baseline interviews were completed with seven participants who could not be reached for follow-up interviews. One patient who was contacted and who consented to participate was subsequently dropped from the study when it was learned, during the baseline interview, that he had metastatic prostate cancer. No additional interviews will be conducted in completing Task 3. Completed interviews were transcribed and entered into the qualitative database.

Task 4: Complete comparative analysis of narratives elicited in three cohorts

Analyses of the interviews conducted in accomplishing Tasks 1, 2, and 3 led to the development of a generic data dictionary for analyzing these accounts of living with prostate cancer. The codes were developed through grounded theory methods, as described in the study protocol. The codes represent and organize the content of the accounts.

Task 5: Complete final report.

**Main Analyses and Findings**

**Survey of Survivor Cohort**

The 33-page questionnaire included a comprehensive set of bodily dysfunction and quality of life measures. Two outcomes of interest in the present study, perceived cancer control and perceptions of one's treatment decisions, were measured by multi-item scales: *Cancer Control* and *Informed Decisions*. Nine other scales assessed additional psychosocial dimensions of prostate cancer-related quality of life. Behavioral, emotional, and interpersonal effects of urinary and bowel dysfunction (e.g., feelings of embarrassment, helplessness; preoccupation with need to urinate or monitor bowels) were assessed by *Urinary Control* and *Bowel Control*. Effects of sexual dysfunction on sexual behavior and self image were assessed by *Sexual Intimacy* (e.g., awkwardness with sexual intimacy and performance), and *Sexual Confidence* (e.g., comfort with one's sexuality). The broader effects of bodily—especially sexual—dysfunction were assessed by *Masculine Self-Esteem* (e.g., feeling oneself to be weak, small or less than a whole man). Related concerns about the relationship with one's spouse or intimate partner (e.g., misgivings about diminished bonds of affection) were assessed by *Spouse Affection*. Feelings of apprehensiveness about future health problems expressed by prostate cancer survivors were assessed by *Health Worry*, while attention to PSA and the comfort of knowing one's PSA level were assessed by *PSA Concern*. Summary appraisals of the success of one's coping with prostate cancer were assessed by *Outlook*. *Regret* relating to the choice to pursue a

particular course of was defined by five items that captured feelings of having made the wrong choice of treatment and a wish to revisit and change that decision.

*Cancer Control, Informed Decision*, and the nine other prostate cancer-related quality of life scales were developed as a set of patient-centered measures of the outcomes of treatment for early prostate cancer.(1) These scales encompass aspects of behavior and well-being beyond the relatively restricted definition of quality of life provided by measures of the severity of physical symptoms. Scores on *Cancer Control, Informed Decision*, and the other nine prostate cancer-related quality of life scales ranged from 0 to 100, with high scores indicating higher levels quality of life, except for *Health Worry* and *PSA Concern*, where high scores indicated greater worry or concern. The measure of regret, which fortunately is denied by most men, is a dichotomous variable, with men who express relatively frequent feelings of regret scored as regretful.

Diagnostic data, including pre-treatment PSA, Gleason score, and stage, and primary treatment, were derived from medical record review. Treatments received subsequent to the first six months following diagnosis, including androgen deprivation and treatments received at sites other than those where study participants had been recruited, were assessed by self report. Androgen deprivation therapy was ascertained by asking men whether they "had started a long term course of hormone treatment (injections or pills) for more than 12 months or that you continue to receive" or had undergone "an operation in which your testicles were removed (an orchiectomy) in the months or years after the first six months following diagnosis. PSA levels subsequent to primary treatment were assessed by self report, using items developed by Fowler and his coworkers in their survey Medicare beneficiaries undergoing androgen deprivation.(2)

The data analysis was focused on examining variation in two scales: Cancer Control and Informed Decision. The distributions of scores on these scales, shown in Figure 1, indicated substantial ceiling effects and negative skew, as had been found in previous survey data.(3) Hence, both of these scales were reduced to three-level ordinal measures. Scores equal to or greater than 80 were considered "high," scores between 60 and 79, inclusive, were "medium," and scores less than 60 were "low." These cut points correspond to responses to the items comprising these scales, including positive and negative statements that could be endorsed or rejected on a five point scale. A score of 80 or higher on these scales indicates that on average a respondent tended to answer with a strong endorsement (i.e., "very much") of positive statements and a strong rejection (i.e., not at all) of negative statements defining the scales. Conversely, a score of 60 or less indicates that responses to positive statements were equivocal (i.e., "somewhat") or a rejection, while responses to negative statements were equivocal or strongly endorsed.

We examined univariate associations between these two scales and demographics, diagnostic variables, treatment, subsequent PSA, urinary, bowel, and sexual dysfunction and bother, and prostate cancer-related quality of life. Associations with categorical variables were evaluated using chi-square, while the median test was used to test associations with age at diagnosis and years since treatment. Associations with symptom indexes, bother scales, and quality of life scales were evaluated using Spearman's correlation coefficients for ordinal variables.

In order to evaluate the joint effects of these variables we estimated ordinal logistic models for Cancer Control and then for Informed Decision. Models were built systematically in four steps. In the first step, we evaluated the effects of demographic, diagnostic, and treatment

variables with at least marginally significant ($p < .10$) univariate associations with the outcome. We used a stepwise procedure with backward elimination in which variates with non-significant coefficients ($p < .05$) were deleted. In the second step, we evaluated the effects of treatment-related bodily dysfunction by including the symptom indexes and symptom-bother scales, along with variables retained from step 1. In the third step, we evaluated the effects of prostate cancer-related quality of life scales, along with covariates retained in steps 1 and 2. Finally, in the fourth step, we included measures of overall functional status and well-being, health perceptions, stigma, and social support, along with covariates retained in the prior three steps. In each step we included variables with significant ($p < .05$) univariate associations with the dependent variable. This four step process was followed first with Cancer Control as the dependent variable and then with Informed Decision. All analyses were performed using SAS procedures.

*Results.* The response to this mail survey was quite high; 235 (87%) of 269 surviving patients for whom we could obtain valid addresses returned completed questionnaires. Ten men explicitly refused to participate, three of whom indicated they were too ill; 24 failed to return a questionnaire after being sent reminder post cards and then second questionnaires, and being contacted by telephone. The response rate is noteworthy, given the passage of time since these patients had participated in the previous cohort study. At minimum, the respondents had completed their 36-month follow-up assessments in the preceding cohort study 12 months previously. For about 30%, the interim between that last follow-up and their receiving the present questionnaire was four or more years.

At diagnosis, these patients were median of 64 years old. Most were married and highly educated. Most had undergone either radical prostatectomy (33%) or external beam radiation (41%), while 18% pursued brachytherapy. Most of the latter were accrued in the latter part of the cohort study, which had been extended in order observe the reemergence of this therapy for early prostate cancer in the late 1990's. Androgen deprivation therapy, subsequent to primary therapy, was reported by 15%. One-fourth said their PSA had started to go up again after their first treatment, but 66% said their doctors had most recently told them their PSA was stable and 37% reported virtually undetectable PSA.

Most of these men expressed a comfortable understanding that their prostate cancer was under control. It was not an object of significant concern for 66% of the respondents, who indicated by high scores on *Cancer Control*, illustrated in Figure 1. A slightly smaller proportion of these men, 57%, indicated high confidence in their treatment decisions, feeling that they were well informed and satisfied with their choices. Conversely, 14% reported low levels of cancer control and 15% reported poorly informed decisions. Cancer control and decision confidence overlapped somewhat; 43% reported both high levels of cancer control and informed decision, while 21% expressed misgivings (i.e., low to moderate scores) about both cancer control and the quality of their decision making (data not shown). The correlation between these two outcomes was modest: $r = .32$.

Perceived cancer control was associated with satisfaction with treatment for prostate cancer and global appraisals of it outcomes, that is, "with the way things have turned out since you found out you had prostate cancer." Patients' confidence in their treatment decisions was also associated with satisfaction with treatment and overall outcomes. Conversely, diffidence in decisions had a marked association with regret. While 7% of the total sample expressed regret, 23% of those who felt their treatment decisions were poorly informed wished they had chosen a different approach. In addition, feelings about the quality of one's treatment decisions were

associated with responsibility for the decisions was recalled, as men feeling little confidence more likely to assign greater responsibility to their doctors.

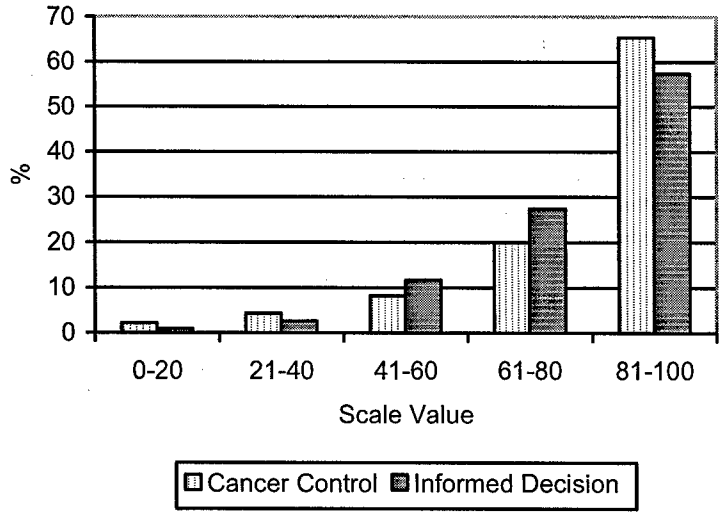


**Figure 1. Distributions of Scores on Cancer Control and Informed Decision Scales**

Perceptions of cancer control were negatively associated with Gleason scores from clinical biopsies performed four to eight years previously. Patients with low or moderate Cancer Control were twice as likely to report total Gleason scores greater than 7. Cancer control was not significantly related to PSA level at the time of diagnosis, but there was a clearly negative association with subsequent rises in PSA. Perceived cancer control was not significantly associated with type of primary treatment, but men survivors who were concerned about poor cancer control were much more likely to report subsequent androgen deprivation treatment.

Unlike cancer control, patients' confidence in their treatment decisions was associated with marital status and, marginally, with age. Confident men were more likely to be married and somewhat younger. Confidence in treatment decisions was also associated with the chosen treatment. Men who were who felt high confidence in their decision making were more likely to have chosen radical prostatectomy, while the diffident had more frequently chosen external beam radiation. Feelings about treatment decisions were not significantly associated with subsequent androgen deprivation, and they were not at all associated with subsequent rises in PSA. However, men who expressed misgivings about their decisions had lived with them longer time.

Both perceived cancer control and confidence in treatment decisions were associated with the severity of treatment side effects and quality of life. Only confidence in treatment decisions was associated with relevant domains of bodily function at baseline, and then only sexual function. Men who felt poorly informed and unsatisfied with treatment decisions made four to eight years before were slightly worse sexual dysfunction at the time they were making those decisions. Current levels of urinary obstruction, but not incontinence, and bowel problems were

associated with poorer scores on both outcomes. Confidence in decisions was diminished by current, post-treatment sexual dysfunction. In addition, we also evaluated associations between changes in symptom indexes, i.e., increases, from pretreatment to 24 months after treatment, when long-term complications would be stable, and these two outcomes. Neither Cancer Control nor Informed Decision scores were associated with *increased* urinary, bowel or sexual dysfunction in these long term survivors.

Relatively poorer prostate cancer-related quality of life was associated with lower levels of perceived cancer control and greater diffidence in treatment decisions. In particular, *Health Worry*, which indicates apprehensiveness about possible bad news about one's health in the future, including cancer recurrence, was strongly correlated with perceived cancer control ($r = -.56$). However, neither PSA concern nor appraisal of the effect of surviving cancer on one's outlook were significantly associated with perceived cancer control. Both of these dimensions of quality of life were positively correlated with confidence in decisions. *Sexual Confidence* and *Martial Function* were associated with greater confidence in treatment decisions. Behavioral and emotional problems associated with poor bowel control were associated with greater misgivings about cancer control.

Confidence in decisions was positively associated with both pre-treatment and current/follow up physical health, as measured by the Physical Component Summary of the SF-36, while current mental health increased with increasing perceived cancer control. Both outcomes were also aligned with more optimistic health outlook, greater social support, and less feelings of stigma.

The multivariable models that were constructed to examine the joint effects of these variables on *Cancer Control* and *Informed Decision* are presented in Tables 4 and 5. The likelihood of a high level of perceived cancer control was decreased by a pretreatment Gleason score of 7 or greater, androgen deprivation therapy, and evidence of PSA failure, including a rising PSA after initial treatment, being told by one's doctor that one's PSA is rising, and a current PSA greater than 1.0. In the multivariable model, bother with bowel symptoms also associated with diminished decreased cancer control, but univariate associations with severity of bowel symptoms and urinary obstruction failed to remain significant. In addition, sexual confidence was associated with increased cancer control. However, this effect, along with that of bowel bother, was reduced to insignificance when health worry was considered in the model. Overall mental health status, other health perceptions, stigma, and social support had no significant independent effects on cancer control, relative to pre-treatment Gleason score and subsequent androgen deprivation and rising PSA.

A different picture emerged in developing a model to account for confidence that one's treatment decisions were well informed. The likelihood of confidence increased with being married and having chosen radical prostatectomy or brachytherapy, rather than external beam radiation. Bother with sexual dysfunction reduced confidence, while other measures of dysfunction and bother had relatively no effect. Masculine self esteem and PSA concern were both associated with greater probability of high confidence. However, the effect of masculine self esteem attenuated when social support and health worry, both with strong effects, were considered in the model. Conversely, stigma and perceived physical health had no independent effects on how men perceived the quality of their treatment decisions.

Since the univariate analysis indicated that Spouse Affection and the MOS Marital Function scales were significantly associated with the two outcome variables, two additional sets

of models were developed to evaluate the effects of these variables in conjunction with other covariates. These models were restricted to the subset of patients who were married or had a person they identified as being like a spouse; marital status was not included in the models. The final models were similar to those obtained with the full sample. Spouse Affection was retained as a significant determinant of cancer control, along with sexual confidence, health worry, pretreatment Gleason score, androgren deprivation, and post-treatment rising PSA. In the case of Informed Decision, Marital Function was a significant determinant of a high score, along with choice of radical prostatectomy or brachytherapy, and sexual dysfunction, although the effect was diminished to nonsignificance with the addition of social support and health worry.

**Table 4. Summary of Sequential Stepwise (backward) Logistic Model: Cancer Control**

| | coeff | p | coeff | p | coeff | p | coeff | p |
|---|---|---|---|---|---|---|---|---|
| Gleason = 7 | -.89 | .007 | -1.09 | .002 | -1.06 | .003 | -1.13 | .016 |
| Androgen deprivation | -.92 | .023 | -1.17 | .007 | -.79 | .082 | -.1.31 | .016 |
| PSA went up | -1.06 | .002 | -.92 | .012 | -1.21 | .002 | -.98 | .029 |
| PSA rising | -2.07 | <.001 | -2.03 | <.001 | -1.79 | <.001 | -1.78 | .001 |
| PSA > 1.0 | -.86 | .009 | -.91 | .009 | -.87 | .017 | -.65 | .100 |
| Bowel bother | | | -.03 | .018 | -.02 | .068 | -.01 | .405 |
| Sexual confidence | | | | | .02 | .004 | .01 | .27 |
| Health worry | | | | | | | -.08 | <.001 |
| c statistic | .764 | | .792 | | .792 | | .870 | |
| Variables Removed | Gleason > 7 | | urinary obstruction<br>bowel dysfunction | | urinary control<br>bowel control<br>sexual intimacy<br>masculine self esteem | | MCS 12<br>health outlook<br>health change<br>stigma<br>social support | |

**Table 5. Summary of Sequential Stepwise (backward) Logistic Model: Well Informed Decision**

| | coeff | p | coeff | p | coeff | p | coeff | p |
|---|---|---|---|---|---|---|---|---|
| married | .75 | .030 | .81 | .035 | .84 | .031 | .47 | .235 |
| radical prostatectomy | .81 | .008 | .86 | .009 | .78 | .017 | .82 | .018 |
| brachytherapy | 1.49 | .001 | 1.58 | .001 | 1.62 | .001 | 1.69 | .001 |
| sexual bother | | | -.01 | .006 | -.01 | .066 | -.01 | .157 |
| masculine self esteem | | | | | .03 | .003 | .01 | .427 |
| PSA concern | | | | | .01 | .021 | .01 | .010 |
| social support | | | | | | | .03 | <.001 |
| health worry | | | | | | | -.03 | .005 |
| c statistic | .654 | | .682 | | .740 | | .787 | |
| Variables Removed | external radiation<br>years since treatment | | baseline sexual dysfunction<br>urinary obstruction<br>bowel dysfunction<br>bowel bother<br>sexual dysfunction | | bowel control<br>sexual intimacy<br>sexual confidence<br>effect of cancer on outlook | | PCS-baseline<br>PCS-follow up<br>health outlook<br>stigma | |

## Components of Survivor's Narratives

Qualitative analysis of men's narratives of prostate cancer has allowed us to explore personal transitions associated with diagnosis and treatment for early prostate cancer. Each man provided narrative accounts of their experiences with diagnosis, treatment and treatment sequelae, as well as accounts of their personal lives, family lives, and personal histories. In this sense, the accounts are viewed here as situated accounts men's lives with prostate cancer. That is, men portrayed themselves as survivors or victims of prostate cancer, and did so by providing rich context about their lives.

The interview thus can be considered a situated accounting of each man's life with prostate cancer. It consists of that which each man chooses to reveal to the particular interviewer in the context of a study on prostate cancer quality of life. The following are moments of the account, that is categories that capture significant aspects of the account provided by men in their interviews: 1) disease; 2) disease acts; 3) physical dysfunction; 4) social context and 5) identity.

***Disease***

The men talked about cancer, cancer control, and mortality as it relates to cancer. These segments are marked to explore ways in which men experience their cancer. In addition we marked discussions about other comorbid disease in order to understand the context of health and illness, both past and present, that may be related to how men view their cancer.

The interviews with the men who participated in this study of course contained many references to prostate cancer. However, in listening to what they said, we noticed that they would speak both about cancer as a general category of disease experience that would threaten their survival and peace of mind, and prostate cancer in particular as the relatively specific, problematic disease that diminished the quality of their lives. Hence, we developed a set of "Cancer" codes in order to capture the various ways in which these men talked about both the particular and the more generalized disease that had compelled their attention.

Our analysis has identified seven principal attributes of cancer that are represented in the accounts of men with prostate cancer. First is *cancer's tendency to grow, steadily and progressively*. The men would impute a history of cancer growth prior to their diagnosis. They would presume that their cancers would have grown relentlessly if they had not been treated. Second is *cancer's controllability*. Treatment could provide control, although the men varied in their estimates of the probability and of control. Some felt that the progress of their cancer was, or should have been, arrested by undergoing surgery or radiation therapy; others thought that therapy might only retard the relentless growth of the disease. Third is *cancer's visibility*. Prior to diagnosis, prostate cancer had been largely invisible, with no symptomatic or other manifestations. Some men recalled previous PSA tests as having little relevance as "cancer." However, since treatment, PSA levels acquired considerable import as vital indicators of an otherwise occult disease.

The fourth and fifth attributes of cancer concern *the personal relevance* and *personality of prostate cancer*. With respect to the former, prostate cancer was construed by some men as part of their person. It was personal, embodied disorder. For others, it was identified as an external object, afflicting them but not part of them. Related to this way of talking about prostate cancer, the fifth attribute had to do with the personality that some men ascribed to their cancer,

and cancer in general. Cancer was characterized as having agency of its own. It had volition as either a problematic part of oneself, or as an alien antagonist.

Finally, two attributes reflected the ends of cancer. One was cancer's quality as a *typically fatal disease.* The growth ends in death. The other was the *progressive diminishment of oneself* in the face of cancer. Cancer eventually involves wasting away, with loss of function and dignity.

These seven attributes, although not explicitly mentioned by every man who was interviewed, and varying in the details of their use as descriptors, comprise the ways in which the underlying object that set the stage for men's accounts of treatment and quality of life outcomes. The genesis of their problems in their lives since treatment was this disease that could be visible or invisible, signified by PSA values, an uncomfortable part of them or a malevolent actor *who* had entered their lives.

***Disease Acts***

These segments refer to actions taking with regards to the cancer itself. They include 1) discovery, 2) decision account; 3) account of treatment. Discovery refers to the way in which the man says he found out about the cancer. This may include PSA testing, biopsies, and the actually receipt of the diagnosis. It also includes symptoms a man says he had that made him concerned. The account of the treatment includes anything about how it was to undergo treatment.

Decision account is the account provided about coming to a decision about which treatment to undergo. Decision account was subcoded to explore what kinds of things contribute to a man's decision to undergo a particular kind of treatment. Rather than focusing solely on survival or the importance of treatment side effects for each man, this analysis extends decision making . We considered:

1) Agency: Who makes the decision? The primary decision maker is sometimes the man himself and at other times the doctor alone. However, most men described a situation in which the man, doctor and sometimes spouse or family member made the decision together.
2) Mediators:
    a. What are the different kinds and sources of information men use to make the decision? Men may rely solely on the information provided by a single physician or may consult multiple physicians from different specialties. However, some men did not only rely on physicians. Rather they drew on information provided by friends and family who had prostate cancer, information culled from the press and Internet or from books and medical journals.
    b. What kinds of treatment complications are considered to be of importance to that individual? Some men considered the potential for urinary, sexual and bowel dysfunction as important in choosing a treatment. For some men, complications were not considered, and the sole consideration for deciding up on the treatment was how well the treatment was perceived to be able to control or cure the cancer. Others chose treatment that was most conventional – that is, they believe that this is what is usually done.
3) Problem: What is the nature of the problem? Some men perceive cancer to be more serious and urgent than others. Some see it as life threatening. Others see it as a medical

problem to be dealt with, removed and cured. Others still see it as life altering, affecting the ways in which they see themselves and their lives.

4) Perceived options: Many men we spoke to did not perceive that they had any options available to them. Some simply thought that there was only one possible treatment, while others believed that due to their age or the kind of cancer, they could only have one type of treatment.

For example, one man may simply take the advice of his doctor to have surgery without consulting others, read little about the cancer, not consider the side effects or seek out other information about the cancer, perceive few options for treatment and consider the problem simple – just to remove the cancer and move on. In contrast another man may seek the advice of many, including friends and family, may make the decision with his wife and his doctor, may carefully consider the impact of potential incontinence and erectile dysfunction as well as the possibility of cure, and may seek information from multiple sources including the internet, newspapers and journal articles. This man may see the problem of cancer as being unsolvable, ongoing and serious, and may perceive that there are many options, all with potential benefits and potential drawbacks. These illustrate the complexity of making a decision about prostate cancer and men experience the decision making process very differently.

***Physical Dysfunction***

The risks of bodily dysfunction associated with treatment for early prostate cancer are well known to physicians and patients alike. They are increasingly well characterized in the clinical research literature.[2] While these bodily changes are believed to have substantial effects on men's quality of life, the nature of these effects has heretofore largely been limited to assessments of *bother*. Our recent work, informed by qualitative studies of men's perceptions, has produced more broadly encompassing psychometric measures of prostate cancer-related quality of life.[3,4] The extensive qualitative study undertaken in this project now allows us to construct a richer and more nuanced characterization of quality of life as it relates to the bodily dysfunction that results from treatment. We will focus on urinary incontinence and sexual dysfunction, the two most common, problematic side effects of treatment.

*Urinary Dysfunction*

Urinary incontinence is a frequent outcome of radical prostatectomy and brachytherapy for early prostate cancer. Not surprisingly, many of the members of the two cohorts from which interview subjects were drawn reported at least occasional urinary leakage in the past week, with 10% of the VA/HVMA cohort reporting little to no control of their urine at all. More than 10% said they wore pads in their underwear or garments typically referred to as "diapers."

| **Prevalence of Urinary Incontinence in Two Survey Samples of Men Treated for Early Prostate Cancer** | **1999 Survey of VA and HVMA Patients** | **2002 Survey of MGH Cohort** |
|---|---|---|
| Leaking urine in the past week | percentages | |
| not at all | 46 | 59 |
| occasionally | 44 | 40 |
| most of the time/no control | 10 | 1 |
| Wore absorbent pads or "diapers" in the past week | 17 | 13 |

The qualitative analysis of the accounts of urinary problems presented in the interviews defined five major thematic categories.

**Major Themes of Men's Accounts of Urinary Problems**

- Physical experiences of urination and controlling urination
- Practical problems in dealing with impaired urinary control
- Etiology of urinary problems
- Communication about urinary problems
- Effects of urinary problems on emotional well-being and self-image

*Physical experiences of urination and controlling urination.* At the most basic level, talk about urinary dysfunction revolves around the actually urinating and the physical capability of controlling urination. Hence, the men described "leaking," "spraying," and a diminished ability to urinate standing up, as men typically do. Voiding, for some, had become a rather complicated affair.

Data Extract 1

P: A related problem is my inability to 1727
urinate in the normal manner by 1728
standing male fashion at the toilet. 1729
I: Hmm. 1731
P: The removal of a portion of the 1733
ureter with the prostate has made my 1734
penis about one inch shorter, reducing 1735
my ability to aim in the appropriate 1736
way. 1737
I: [Mm-hmm.] 1739
P: [Therefore,] whenever possible I 1741
relieve myself in a cup and then empty 1742
the cup, and in this way avoid 1743
splashing. In addition, it takes two 1744
hands to accomplish this procedure 1745
with my pants loosened and partially 1746
pulled down over my hips. This 1747
partial exposure of my backside has 1748
been misinterpreted on two occasions 1749
in a men's room. How does one relate 1750
this to the quality of life? 1751

**Comment [j1]:** Urinary Characteristics

**Comment [j2]:** Urinary Charact. – modified urination

**Comment [j3]:** Interpersonal

Those who completely lacked control were mindful of the risks of accidents, since urination could occur silently.

Data Extract 2

I: Tell me about it. Have you ever had 1397
an accident? 1398
P: Oh yeah. Yeah, I was at a hall one 1400
night and we were standing there and 1401
jeez I looked down and a big puddle 1402

**Comment [j4]:** An **ACCIDENT** story. Illustrates uncertainty, not knowing what can effectively be done.

under my foot. Never felt it. It 1403
just ran right down. And I just 1404
walked away and walked into the men's 1405
room. The pad was all gone and I was 1406
soaking wet. You just can't feel it 1407
sometimes. It just comes right out. 1408
If I cough I can feel it, but there's 1409
other times, it just runs right out. 1410

Urinary incontinence is essentially an impaired ability to control the emptying of one's bladder. This specific impairment was highlighted by many of the men we interviewed, in a way that is typically overlooked in quality of life research. Whereas most mature men urinate and delay urination at will, but with little thought, urinary dysfunction in the men we interviewed was commonly experienced as a heightened awareness of self control and struggles to exert control. Men can usually recall learning, as little boys, to "hold it." It is part of socialization by parents and kindergarten teachers. Men can also think of times when, as adults, they have faced challenges in this area, such as the long line at the men's room at half-time during a football game. However, many of the men we interviewed reported a renewed and constant awareness of the need to "hold it." They might mention, sometimes by name, the Kegel exercises they had been taught after surgery. Yet, more frequently, they described self-consciously exercising their urinary sphincters as part of their everyday life. Sudden urges were particularly problematic.

Data Extract 3

P: Depending on how your body's 2357
reacting on a particular day. Um, 2358
also you can't, uh, I-I find you have 2359
to urinate more frequently and you 2360
can't hold it like you could, force 2361
yourself to hold it. So like say if 2362
y-y-you're driving, you're out 2363
someplace where you don't have ready 2364
access, it can very painful, very 2365
painful to hold back. 2366

Comment [j5]: HOLD IT

Comment [j6]: Deliberate self control is painful.

But, Kegel exercises became newly reacquired daily practices and personal accompaniments of otherwise ordinary social interaction.

Data Extract 4

I: Help me understand better. Tell me 299
what a typical day is like in dealing 300
with incontinence. 301
P: Well, I-- coughing is like 303
{inaudible} padding city and as I'm 304
sitting with you now, I'm trying to 305
Kegels because I'm so used to doing-- 306
trying to do them all the time, I'm 307
doing them all the time. 308

Comment [j7]: HOLD IT
Deliberate self control; constant Kegel

*Practical problems in dealing with impaired urinary control.* Urinary dysfunction brought men manifold practical problems. They became aware of limitations of the temporal, social, and geographical range of their activities, that is, how long they could "hold it" or how far they could go before attending to their urinary needs. They described a vigilance that was

focused both inward, on sensations of a need to urinate or signs of leakage, and outward, on the locations of toilets and opportunities to withdraw from social situations when necessary. They also described the complicated, often unpleasant, and embarrassing business of dealing with pads and other prosthetics to cope with failures to exert bodily self control.

Data Extract 5

P: Uh, another thing is that, uh, I 890
tend to think, uh, if-- if I were-- 891
I'm going to be somewhere over night, 892
uh, is it, uh, very convenient or 893
handy to a bathroom. 894
I: Mm-hmm. 896
P: And perhaps don't do some things now 898
and then if I don't think that will be 899
the case. I stay, oh, quite often 900
over night, uh, I go out to my son's 901
on Sunday afternoon and stay overnight 902
Sunday night and Monday. Uh, so, uh, 903
that's okay. Uh-- But, uh, as far as 904
staying over night, uh, anywhere else, 905
uh, it's a consideration. 906
I: Uh-huh. 908
P: Uh, let's see. I went to, uh-- I 910
did go to, uh, fiftieth college 911
reunion, 912
I: [Wow] 914
P: [uh,] last May, but, I, uh, had an 916
opportunity t-to ask to be located 917
near a bathroom and there was one next 918
to the room that I was put into. 919

**Comment [j8]: Behavioral Limitations**
Nocturia limits activities—where he can travel overnight.

---

Data Extract 6

I: Yeah. Have you ever been in a 871
situation where you couldn't get to a 872
bathroom? 873
P: Yeah, uh, the-the before I realized 875
what was going on, I went for one of 876
my four-mile walks 877
I: Mm-hmm. 879
K: and it was in the middle of the 881
winter-well, middle of the winter, it 882
was early in the spring, and it was in 883
1996, and, uh, when I was a 884
half-an-hour, half-a-mile from home, 885
uh, it just didn't work anymore, 886
I: Mm-hmm. 888
P: and I came home pretty badly 890
soaked. 891
I: Hmm. 893
P: But that was-- That basically taught 895
me that--what the limits of my 896
capability are. 897
I: Mm-hmm. 899
P: After that, I made appropriate plans 901
that I--that kind of thing wouldn't 902

**Comment [j9]: Parameters Rehabilitation**: learning from unpleasant experience

happen anymore, 903

---

## Data Extract 7

I'm usually carrying two 317
pads with me because I'm afraid that 318
the other thing will get so heavy, and 319
you know it gets heavy and gets 320
uncomfortable and I guess I'm just 321
getting adjusted to it, now. I don't 322
know. I'm not as frustrated about it 323
as I was because, jeez, I used to go 324
crazy. My wife would say to me, 325
"Don't worry about it. Women go 326
through the same thing." And I'd say, 327
"Don't you know men and women are 328
built different." You know, women can 329
stick the pad up there and I guess 330
they can control it much easier than 331
men. I just-- I have to stay 332
conscious of it all the time. I have 333
to stay aware and it's only within the 334
last year or so that I'm comfortable 335
enough to wear-- I can wear light 336
clothing. Like khakis and stuff like 337
that because you know, if you get a 338
stain on-- you get a little leak on 339
black khakis they don't show as much 340
as the white ones, you know. So I'm 341
getting more comfortable wearing 342
khakis and that kind of stuff. So I 343
just attribute that to my resignation 344
of the fact that this is what's going 345
to go on and I'll probably be buried 346
with a pad on. 347

**Comment [j10]:** Prosthetics

**Comment [j11]:** Interpersonal
Tension with wife.

**Comment [j12]:** Hypervigilance;
constant awareness

---

## Data Extract 8

I: Have you ever not done something 1373
because of the continence problem? 1374
P: Well I've cut out the golf. And at 1376
the time, I was saying it was because 1377
my hands were getting the arthritis in 1378
the hands, I was losing. But I think 1379
most of it was because I was worried 1380
about the continence. Every time you 1381
swing the club, you get a spurt. But, 1382
you know, I see all these guys out 1383
playing, you know, Arnold Palmer and I 1384
say to myself, you look and you can't 1385
tell and you say to yourself, "Has he 1386
got a pad on, too?" How do you know. 1387
You don't know. You know, you say he 1388
seems to be doing all right. What the 1389
hell is the matter with you? So I'm 1390
back to doing just about everything I 1391
ever did. But there's always that 1392
caution. You're always kind of aware 1393

**Comment [j13]:** Behavioral
Limitations
Avoid behaviors; end lifestyle pursuits

of what you're doing. I suppose that 1394
comes with age. 1395

---

Data Extract 9

I: What happens when you're in a new 681
place, where you don't know where 682
things are? How do you manage? 683
P: Well, you just have to use field 685
expedients (?). You just use whatever 686
is available. You get out. You fix 687
the car. You do whatever you have to 688
do. Because when you have to go, you 689
have to go. 690
I: Do you ever not go to places because 692
you might have a problem? 693
P: Yes. If there's no bathrooms in the 695
immediate area, that I might have to 696
go-- If I have to sit too far from one 697
of them, then we won't go. Because I 698
know I'm going to have to go. 699

**Comment [j14]:** Behavior to manage voiding – improvise when necessary

*Etiology of urinary problems.* The second general category we identified is the *explanation of urinary problems*. It includes issues of agency and etiology. Men differed in how they explained their urinary dysfunction in terms of who or what is responsible for the malady, to what the man attributes the cause and to what extent they themselves have control over what occurs in their daily lives. Some men blamed themselves for the choice of treatment, most often surgery, that left them incontinent. Others blamed the surgeon whose, 'slip of the knife,' or incompetence caused the incontinence. Further some men stated that they were unaware of the possibility of incontinence with a given treatment, or were unaware the extent to which this would occur.

Data Extract 10

Uh, sometimes I 1443
wonder when the doctor took out my 1444
prostate, did he get everything back 1445
right, you know. Because sometimes in 1446
the morning, I'm like get out-- Get 1447
out of my way. I got to get in and 1448
urinate. So. Even dur-during the 1449
day.

**Comment [j15]:** Etiology – mishap of treatment; blame doctor

**Comment [j16]:** URGENCY

---

Data Extract 11

And some guys can have 489
these operations and they don't have 490
that much of a continence problem. 491
Because I said to him, "I don't have a 492
continence problem now. Why would I 493
have one after I'm operated on?" 494
After the operation, I end up with 495
incontinence. That's the fault of the 496
doctor, it's not my fault. That's the 497
way I look at it. Well you know 498
there's different things about it, as 499

**Comment [j17]:** Etiology: medical mishap

you know. I feel that if I was having 500
a leaking problem before I was 501
operated on, I could understand it. 502
But if I wasn't. Then, you know, they 503
give you the well, you know how much 504
work they had to do to get it all out 505
and make sure everything was clean; 506
which is probably true. You know, 507
there's probably truth in everything 508
that is being said. How many grains 509
of truth, I don't know. 510

---

Data Extract 12

P: And, uh, *Dr. Name*, the last time I 3042
saw him, which was more than a year 3043
ago, said well, "Just be patient, 3044
sometimes it takes a year, sometimes 3045
it takes two years." [So,] 3046
I: [Mm-hmm] 3048
P: I said, baloney, it just took two 3050
seconds of that crazy knife of yours. 3051

**Comment [j18]:** Etiology

References to the etiology of urinary problems were also present in accounts of avoiding or escaping these problems. Men were mindful of the risks they had been asked to run.

Data Extract 13

I: Mm-hmm. {pause} He recommended 633
the radiation, um, and he said the 634
operation wasn't going to be indicated 635
for you? 636
P: Yes. 638
I: Sounds like you took that as a 640
relief? 641
P: Oh, absolutely. Yes. 643
W: Well, after Joe's experience where 645
he, uh, he had {pause} He-[he-he] 646
P: [And he lost] [control of his, uh,] 648
W: [Yeah, he]-- He lost bladder 650
control. 651
I: Yeah. 653
W: And, uh, I keep {inaudible} to this 655
day, and this is at least four or five 656
years for him, he still needs, uh, 657
protection. 658

**Comment [j19]:** Avoided UI by MD recommendation (as opposed to chose Rx to avoid UI, and oppsed to escaped UI). UI is presented as the awful that didn't happen.

---

Data Extract 14

P: But then he explained that he 3124
couldn't guarantee that he could save 3125
both bundles of nerves, and indeed he 3126
couldn't because there was cancer 3127
there, but I still did okay, even 3128
without that. 3129
I: Right. 3131

P: But I was in very good, well still 3133
am, I was in very good condition, I 3134
mean so it was-- he said, "It's part 3135
me, part you." But so those fears went 3136
away like, literally, I mean 3137
I: [Yeah.] 3139
P: [I just] don't want to think of-- I 3141
mean, I haven't lest-lost one drop of 3142
urine {laugh} ever. 3143

*Communication about urinary problems.* Communication about these problems was itself problematic, both in interpersonal relationships and in the formal settings of doctors' offices.

Data Extract 15

I: No, okay. And what's it-how is 747
it-You said it's-it's quite bothersome 748
to feel like you have to go every 749
half-hour or [hour {inaudible}]. 750
P: [Yeah, because], uh, you know, uh, 752
you sit at a meeting and you have to 753
excuse yourself in [order to] 754
I: [Mm-hmm.] 756
P: go to the bathroom. Now other 758
people sit through the meeting, no 759
problem at all. 760

Comment [j20]: Interpersonal Interrupt public social interaction

---

Data Extract 16

she thinks I make too big 1290
a deal about the sex and I make too 1291
big a deal about the continence. And 1292
she says, "Just deal with it, that's 1293
all. You're not the only one, women 1294
have it too." That doesn't solve the 1295
problem, but that's what she gets. 1296
And it's just her way of saying don't 1297
make a big thing about it. Deal with 1298
it as is comes along. She can deal 1299
with things fairly well, I guess. But 1300
you know, I say to her, "It's not a 1301
big deal to you, but it's a big deal 1302
to me." And that usually does it. 1303

Comment [j21]: Interpersonal Tension with wife.

---

Data Extract 17

And the only problem I 107
have is leakage. And it's frustrating 108
as hell. And you might as well talk 109
to the wall, than talk to the doctors 110
about it. They don't-- you know. I 111
could understand that their idea is to 112
get the cancer out. But you know, 113
they miss the quality of life for the 114
person that they've taken the cancer 115
out of. So I think, you know, 116

Comment [j22]: UI Subjective Burden

Comment [j23]: Urine Med UI Inattention by doctors

impotence is the big thing. That's gone. And you end up wearing a pad. I've been kind of chasing them around about that. Is there any other way I could do this thing? You know there's got to be-- I feel there's got to be-- with all the technology today, there's got to be something that they can use to-- I know the women have it and they tip their bladder up or some dam thing. I don't know, they put a sling there. And I think-- and I went over to the-- I go to the meeting over at the Name Name [hospital] and they had a doctor in there and he talked about doing the men's sling. But there's nobody around there that does it, I guess. He was from the West Coast. I don't-- it's not a high priority item with the doctors, I guess. The high priority item is to get the cancer out. And I feel he did that. You know he-- you don't get enough information from the doctors when you first get this thing and they first diagnose you. I don't think they give you enough information. They don't give you enough information about impotence, they don't give you enough information about the incontinence. They quote all of these figures to you and it's just a lot of nonsense as far as I'm concerned, you know. And most of them are wrong. But like, I go over to the session where it's all for prostate people and everybody comes out is impotent. It's the rare bird that has it, and even with-- even today with the nerve sparing stuff, there is some success but not as much as they pump it up to be. But I think they're missing the boat on that. I think they undersell the man. I think they think the man would not opt for the surgery with all of these things facing him, you know impotence and--. And I think, I don't know. It gets frustrating when you're trying to find out how-- which-- see somebody who specializes in incontinence and who to see. You never get definite answers. You get all yes and no's and maybes. And I've been doing all these Kegel things and you know, you do so much of that stuff, you say to yourself, am I doing them right. I don't know if I'm doing it right or wrong. You know and I get a lot of my information from the Continence outfit down in South Carolina or wherever it is, it's an association for continence, NAFC.

**Comment [j24]:** Urine Med
Wish for a remedy; anger at the lack of remedy

**Comment [j25]:** Urine Med
Poorly informed by doctors about UI

**Comment [j26]:** Doctors mislead about UI risks

**Comment [j27]:** HOLD IT
Deliberate self control, but uncertain about performance of Kegel

They have a newsletter and everything else.
I: I hadn't heard about those guys.
P: Yeah, well I think if you-- 1-800-BLADDER I think it is.
I: [Laughter] Of course.
P: But they're very good. They're probably help you, send you some stuff. I get a newsletter from them periodically and that gives me little hints and things to do. Sometimes a little bit of knowledge is a dangerous thing. I'm getting all these little bits of information. But I can't find anybody around here that specializes in-- a lot of them specialize in the women's stuff, but none in the men. And I don't think the urologists pay enough attention to it. That's my own opinion. At least the guy I'm dealing with, so I don't know. Because the main function is to get the cancer out. I'm going on six years now, so

*Effects of urinary problems on emotional well-being and self-image.* Diminished urinary control presented challenges to self esteem and risks of embarrassment. On the other hand, coping with these problems and reestablishing a sense of control could be seen as a source of pride.

Data Extract 18

The incontinence I blame on the individual person, because it can stop. There is no reason it can't. The individual, if he's lazy enough, then he's going to be incontinent because you can stop that. But you

**Comment [j28]:** Identity Agency: UI due to lack of willful self control, effort

Data Extract 19

P: They were a pain. Don't like them. So I would wear {laugh}-- I would wear dark undershort and I'd wear my darkest trousers when I knew I was going out in the supermarket and might be there for a long while and something like that would have happened. And once or twice it did happen. I was unable to get out to the car fast enough. And, uh, I did have some leakage. Uh, so, uh, I lived with it, you know. I, uh, I went home and, uh, washed the {laugh}-- washed the trousers and washed the, uh, underwear and, uh-- and, uh, scheduled, uh, my next supermarket appointment {laugh} [a week later.]
I: [{laugh}]
P: So, uh, nothing, uh-- maybe I'm just

**Comment [j29]:** Behavioral Management
Management: dark trousers in anticipated risky situations

**Comment [j30]:** Rehabilitation = lived with it

```
  a shameless person, but I don't, uh, I  703
  don't get shamed too easily.            704
I:  That's fine. [{laugh}]                706
P:  [{laugh}] Fine with me at least.      708
  [{laugh}]                               709
```

Comment [j31]: Subjective Burden
Explicitly reject shame

---

Data Extract 20

```
                I don't want to sound   1426
like a complainer.  It's been okay,     1427
except, you know, it's frustrating      1428
sometimes.  And I think the thing that  1429
frustrating for me is I just think      1430
there should be answer.  Maybe there    1431
is no answer, I don't know.             1432
```

*Bowel dysfunction* was less frequently described, however resulted in much of the same issues as urinary loss of control. For those who did, the impact was significant; men described embarrassing situations and concerns about others discovering that they were incontinent of feces, as well as significant pain associated with this. In addition, men who experienced bowel dysfunction often described pain associated with radiation proctitis and this often prohibited participation in social activities.

Deleted:

*Sexual Dysfunction*

Sexual dysfunction is the most prevalent bodily side effect of treatment for early prostate cancer.**Error! Bookmark not defined.** The focus of most assessments of sexual dysfunction in clinical research is the quality of erections, or "erectile dysfunction." This is often defined as "erections insufficient for penetration." Erectile dysfunction, defined this way, was quite common in the two cohorts from which we drew men to interview.

| Prevalence of Erectile Dysfunction in Two Survey Samples of Men Treated for Early Prostate Cancer | | |
|---|---|---|
| | 1999 Survey of VA and HVMA Patients | 2002 Survey of MGH Cohort |
| | percentages | |
| Erections insufficient for penetration | 68 | 64 |

However, sexual dysfunction is more complicated than that. Outcomes measures, such as the UCLA-PCI, the Expanded PCI or "EPIC," and the Sexual Dysfunction Index we (Clark and Talcott) developed in our previous research, include additional items to assess other aspects of men's physical experiences, such as ejaculation, which usually disappears with prostate cancer treatment, and orgasm, which may persist after treatment.[5,6,7] Nonetheless, these measures focus on merely physical aspects of sexuality. They accurately and appropriately capture bodily changes that are directly affected by underlying pathophysiological side effects of prostate cancer treatment. Yet, they yield a limited perspective on the manifold changes in sexuality that may ensue from these bodily changes, as well as the diagnosis of cancer that men may perceive as life threatening. We characterized some of these complex effects in an earlier qualitative study.[8] In the present study, our analysis of men's accounts of their sexuality, as part of their larger narratives of life after prostate cancer treatment, adds to our appreciation of the complex

character of this domain of quality of life. We sought to describe how the men we interviewed constructed their sexuality. We identified eight facets of sexuality.

| Facets of Sexuality Presented in Men's Accounts of Life after Prostate Cancer Treatment |
|---|
| • Bodily function<br><br>• Drive, interest, libido<br>• Performance and intimate behavior<br>• Use of assistance and assistive devices in support of performance<br><br>• Relational nature of sexuality<br>• Issues of disclosure<br>• Sexuality as vitality<br>• Masculinity |

First, and perhaps fundamentally, they referred to sexuality in terms of a *bodily function* that was, or could have been, altered as a result of surgery, radiation or hormone therapy. Sexuality entailed certain bodily mechanics. While sexuality is often appreciated in these terms, with a focus on erectile capability, the other seven aspects of sexuality define aspects of behavior, disability, interpersonal relationships, and self-image. We identified three attributes of sexuality relating to the accomplishment of physical sexual expression. The men we interviewed distinguished sex as bodily function from *drive*, that is, their desire, interest, and motivation relating to sex, and *sexual performance and intimacy*, which could, but need not, include intercourse. Drive could be characterized as a quality of consciousness or, for some, a more visceral attribute, such as a man's natural chemistry. References to sexual intimacy included actual and potential sexual performance, including feelings of both confidence and anxiety about engaging in intimate behavior. In connection with performance issues, we also noted references to the use of *assistive devices*, including medications and mechanical devices to promote erectile function. These devices could be either helpful and restorative or cumbersome reminders of a loss of natural capability that diminished the enjoyment of sexual intimacy.

Two attributes of sexuality addressed the interpersonal context in which it was embedded by most of the men we interviewed. Distinct from references to sexual intimacy, these men described sexuality as essentially *relational*. They highlighted the ways in which sexuality entailed complex relationships with spouses, partners, and women who could be partners. These other people could be accepting and supportive, critical, challenging or rejecting. For some men, their sense of where they stood as respectable men in their interactions with women was radically altered. In addition, the men expressed varying orientations to *disclosure* of their altered sexuality. Clearly, American society defines many, complicated rules for sharing thoughts, feelings, and interests about sexuality. The men we interviewed indicated that they constrained by these norms. They also reported new problems relating to the management of potentially stigmatizing information about themselves.

Deleted: .

Their constructions of their sexuality entailed constructions of their overall *vitality* and their *masculinity*. With respect to vitality, sexuality was depicted as a principal component of physical well being, viewed as a normal loss that comes with age, or a sign of becoming decrepit prematurely. Put in terms of vitality, the men could be either sanguine or distressed. Moreover, sexuality could be depicted as either central to a man's evaluation of his vitality, or explicitly marked as peripheral as some indicated continued or even renewed vitality, in spite of diminished sexual capability. Finally, men expressed sexuality as aspect of their masculine identity. Again, some men cast sexuality as essential to being a man, while others assigned it a relatively minor role. For those men who expressed sexuality as essential to their sense of self as men, several sought other ways to express their masculinity. Their loss of sexual function was challenging emotionally and often this was not something they discussed with their providers and sometimes not even with their significant others.

*Bodily function*. To be sure, men's accounts of their sexuality after treatment for early prostate cancer revolved around references to bodily function, primarily erectile dysfunction. Physical impairment in this domain was broadly disabling. It prevented sexual intercourse and derailed sexual expression. For some, bodily dysfunction led to diminished social life. Malfunction was viewed as a direct, physical result of treatment. In some cases, it was viewed by as the natural outcome of aging and declining health. In others, sexual dysfunction was a somatic condition, amenable to medical intervention.

*Expression: Drive*. Drive was distinguished from bodily function in most accounts, often in terms of the well worn distinction between weakened flesh and willing spirit. However, some of the men invoked physical metaphors in referring to diminished sexual drive as chemistry or construing it in quasi bodily terms, interrupted by medication just as erectile function had been. Men who reported androgen ablation were aware of the treatment's effects on libido, while others cited medications for other chronic illnesses, such as diabetes and hypertension. Drive could also be diminished by the other bodily changes caused by treatment, including erectile dysfunction and urinary incontinence. Decreased drive meant sexual intimacy, challenged by erectile dysfunction, became effortful, challenging, and unsatisfying. On the other hand, decreased drive ameliorated the frustration that accompanied erectile dysfunction.

Data Extract 21

```
          and since I had the surgery, I  205
  have become impotent.  Viagra don't do  206
  anything for me, or anything like       207
  that.  I do use the pump occasionally,  208
  but mainly I just don't have the        209
  sexual drive.                           210
I:  Did that change suddenly after        212
  treatment, the drive part, or did that  213
  change gradually?                       214
P:  Well, it changed gradually as we got  216
  into it, as I found more out.  And I    217
  would say it got even worse after I     218
  tried Viagra and knew that wasn't       219
  going to happen with me.  And I'm also  220
  diabetic, which doesn't help any also.  221
   So it's just one problem after         222
  another compounding.  And I've got      223
  high blood pressure.  I'm taking        224
  medication to that, which, some of the  225
```

side effects to that is also-- So it's one of those terms that I'm trying to come to live with. I'm not saying that I'm content and happy with it. No, I'm not. But then a person with one leg, he's not happy either, in most cases. But one of the things that I would say is most devastating for me is the loss of sexual function and drive.

---

Data Extract 22

P: Yeah. I used to want to be with my wife maybe once or twice a week; nowadays maybe once a month, maybe once every other month.
I: Does that feel okay to you, then?
P: Yeah, it's a blessing in disguise because I can imagine that if I had the desires that I had five years ago and the capability that I have today, it wouldn't be good at all, I'd be climbing up trees and worse. It would just not do. So in a sense the fact the body chemistry has let up a little and is not making me want to have sex any more often than I do is a good thing.

---

Data Extract 23

I: Hmm. Um, let me talk about one thing that has changed. Um, you said you started taking these pills and it killed your nature.
P: Yeah, it kills my nature completely. You-- Sometime-- You know, you ain't even know you have a, uh, a, a penis until you have to go to the bathroom. And then after you go to the bathroom, it just-- {laugh} it just disappears again. That's it. Don't even know you have a penis. You don't have no des-- I think-- you don't have-- It kills your sex. You don't have no desire to have sex.
I: Hmm.
P: And it sometimes makes your-- Well, me, it makes you feel moody. You know, like just depressed because, you know, yeah, I'm just-- it's mundoon {sic}. Everything is just-- But I-- I'm going to sweat it out. I ain't ready-- I ain't ready for the cemetery yet.
I: No.
P: No, so.
I: Well, how do you feel about that

though? 899
P: [Well, I--] 901
I: You said] it makes you-- makes you 903
a little depressed. 904
P: Well, I was saying-- Well, uh, you 906
don't, uh-- You feel depressed because 907
you don't, uh, you don't know why. 908
You can't, uh, cope with anything 909
that's going around there, you know, 910
like things going-- You, you want to 911
get i-in rhythm of it. You just 912
don't-- you don't feel like you've 913
can--want to join in with um. Like, 914
people that like to have parties and 915
all that. So you sit on the side 916
watching them, you know. That's all. 917
I go to plenty of parties and always 918
dance. Could al--I've been-- always 919
been a very good dancer. And, uh, so 920
here lately, since I've ta-- been 921
taking them, I just decided d-didn't 922
feel like dancing. I don't do that. 923
But I go to the, to, to the affairs, 924
but I just don't get out on the floor 925
and dance anymore. Just takes-- It 926
just takes all your inh-- uh, ambition 927
or whatever you call it away from you. 928

*Expression: performance.* Beyond bodily capability and drive, sexuality involved complicated problems of sexual performance and intimacy. In some cases, the problems arose at the intersection drive, affection, and bodily capability.

Data Extract 24

I: You said a little while ago you 616
started missing it; tell me more what 617
that felt like, or feels like. 618
P: Well I find it hard to describe; 620
Because-- Particularly hard to 621
describe because in terms of personal 622
closeness and things like that, you 623
know. That is not impaired by 624
anything like that. But sometimes 625
we'd like to do-- I'd like to do what 626
I used to do, and the machinery isn't 627
working, and that's frustrating. I 628
don't think I can describe it any more 629
in detail than that. 630
I: That's clear. You said you're 632
able to be close with your wife 633
despite that; has that changed since-- 634
P: If anything, it's gotten better in 636
terms of personal closeness and things 637
like that.
Sunday mornings we lay in 638
bed, get close to each other, hugging 639
and that kind of stuff. But then when 640
I'd like to go further, then I have to 641
use the machine, and, that's-- Well, 642
it's better than nothing, but is not 643

satisfactory. 644
I: When you use the machine you're 646
able to get a satisfactory erection? 647
P : Yeah. Well, marginal, but with 649
assistance it works. 650

Some men reported coping with bodily failures by shifting to alternative practices and forms of expression. For others, however, the inability to accomplish intercourse was completely frustrating. In addition, several men, both married and unmarried, reported anxiety about initiating sexual activity as they anticipated frustrating performances.

*Expression: assistance/assistive devices.* The assistance in performance potentially available from medications, e.g., "Viagra," injections and suppositories, and pumps, was viewed quite positively, as well as with skepticism and accounts of frustration. Moreover, assistance could feel awkward and unnatural. It could extinguish pleasant spontaneity.

Data Extract 25

My sex life 458
relies on mechanical assistance, but I 459
don't need as much anymore as I used 460
to, so that's okay. 461

---

Data Extract 26

They give me-- I tried the Viagra; 215
it didn't work. They gave me Muse 216
(inaudible) one gram, that didn't 217
work. But the (...inaudible) works. 218
But there should be something, a pill 219
you could take that you could-- I feel 220
there should be a pill that you can 221
take that will help you. That you 222
don't need to insert Muse. Just take 223
the pill and go ahead and deal with 224
the-- with a lady. 225
I: Yeah. 227
P: Am I dreaming? Or far--being far 229
fetched or what? 230

---

Data Extract 27

But I do have my bouts of depression, 343
getting down about this aspect, the 344
sexual part of it, and the point of 345
knowing that there's never going to be 346
anything that can be done to correct 347
it, and if-- I guess when you get to 348
that point is when it really sinks in. 349
No praying and all that in the world 350
will not change a damn thing. It's 351
the way it is. That's the way it is, 352
and it's going to be that way. 353
I: You say you have times when you get 355

down on yourself. How often does that happen?

P: I would like to say now and then, but I think about it probably 24/7. It doesn't stop me from functioning, but I've just-- I guess I would say I avoid flirta-- flirta-- oh, I can't get it out-- flirtation with my wife. I kind of withdraw flirtation from my wife. I've kind of withdrawn from that. And a lot of times, she tells me, "You know, you don't have to have sex. You can be lovey-dovey." But one goes with the other one, with me. You just ain't got that drive. The other part just don't come to me. Just like having a sandwich without meat.

I: Yes, I hear you. So she says it's all right, and you can still cuddle, but that's not where you want to go.

P: No, not at all. Not at all.

I: Do you think that's affecting your relationship with your wife beyond that? I mean, are you a little more aloof from her in general?

P: Right, yes, I am. I am. A lot of times, we take-- I know when she gets in the mood like that, I might make sure that I stay downstairs a lot longer. Hopefully she'll go to sleep or something. I don't want to confront her. I don't even want to get into it. I don't even want to talk about it. And a lot of times, it's not fair to her. And I realize it, but then I'm caught in a dilemma of, hey, if you don't have an appetite, you can't eat. And trying to fake it just don't work neither. So I know what I'm doing, and I know why I'm doing it, and I know what caused it, the problems that it causes, but sometimes I just cant help it. Sometimes I just have to say plain, "I'm just not plain in the mood. Don't do it. Don't touch me." And this makes her become withdrawn a lot of the time.

I: You said you tried the Viagra. When did you try that?

P: Probably anywhere from six to seven months after the operation. And then I tried it again probably a year and a half after, and same thing.

I: Just didn't do anything?

P: Nothing. I didn't even get a headache or a hot flash.

I: And how often do you try using the pump? You said you tried it.

P: I wouldn't say-- I would say maybe

every three months. It's just the preparation of it, and it just takes away from the spontaneous of it, as my wife says. And then she'll say that "Your penis is cold," or that it's too hard, extra hard. You know, that's the things we talk about, and we talk about them openly. The band is a discomfort to me, at times.

I: Those times when you've used the pump, how does that come up? Forgive the pun.

P: You mean, do I initiate it?

I: Yes.

P: Sometimes I do. Most of the time, it's something that she does. It would be more me just going along with the program.

I: It sounds like a hard deal.

P: It is. It is more so on her part, trying to appease me. Because then I get down. Then she gets down. And then I said to myself, "You're still left here with your wants and needs." And we practice other forms of sex, you know, for gratification on her part and stuff. But still, {inaudible} I like to have it if I don't use it.

I: So you do what you can to satisfy her.

P: Right.

I: But it is {inaudible} really satisfies you doing that.

P: Well, it's not one way or another with me. I don't get anything out of it. It's something you do. Then you're glad it's over with. Then you can move on and say, "Hopefully I don't have to worry about that for a couple more weeks, a couple more months, or whatever."

*Interpersonal: relationality.* Men's accounts repeatedly documented the largely interpersonal nature of their sexuality. They defined sexual behavior in terms of their current, past or prospective partners, and sometimes lack thereof. Sex was rarely presented as monadic. Women were often presented as compliant, understanding, and being less concerned with sex than men, although there were some remarkable exceptions where women were described as demanding and challenging. Not surprisingly, marriage defined a significant, normative context for men's sexuality. A number of men cited their obligations as husbands to satisfy their wives sexual needs. Marriage was construed in very traditional terms as the only context for sexuality. Hence, some men suggested that absent a marriage, they had no obligation and thus no experienced no meaningful impact on the quality of their lives due to sexual dysfunction. Related to this were arguments to the effect that diminished interest on their wife's part negated the problem that married men could have experienced. Conversely, marriage provided an essential context for adapting to impaired bodily function. Men expressed satisfaction that they

could still meet their obligations or explicitly noted that their wives had absolved them of responsibility.

Data Extract 28

```
P:  I've told her that I doubted I'd      1375
  have married her, uh, if, uh, if I      1376
  knew what I knew.                       1377
I:  Mm-hmm                                1379
P:  About my sexuality.                   1381
I:   Right.  Right.  What does she say?   1383
P:  Well, she accepts that.               1385
I:  Yeah.                                 1387
P: Uh she's-- She's about six years       1389
  younger-- She is six years younger      1390
  [than I am.]                            1391
I:  [Uh-huh.]                             1393
P: You know?  So, uh, but, uh {pause}     1395
  That's it.                              1396
```

---

Data Extract 29

```
          Um, there was, uh, of course,   564
  a matter of-of perhaps of affect on,    565
  on sexual, uh, uh, ability, uh.  Um,    566
  I'm not sure how much I thought about   567
  that, really.                           568
I:    Uh-huh.                             570
P:  For one thing, at this point in my    572
  life, uh, I was not married.            573
I:    [Right.]                            575
P:  [And,] uh, I was-- I was getting      577
  older.  And, uh, uh, didn't feel I had  578
  any significant prospects for-- For     579
  a--                                     580
I:    [Uh-huh.]                           582
P:  [New] relationship after having       584
  divorced twice.  Uh, my first wife and  585
  I were married for 19 years.            586
I:    Mm-hmm.                             588
P:  And had three children.  And, uh,     590
  then, uh, I was married-- Ann, oh,      591
  after three-- Three years or so.  And,  592
  uh-- A woman who had been married       593
  before and was a few years younger      594
  than I was.  And had two--two chi--     595
  Two chi-young-- Two boys in school--    596
  Of school age.  And, uh, so, I was,     597
  uh, stepfather for twelve years or so.  598
I:    Mm-hmm.                             600
P:  While we were married.  We didn't     602
  have more children.{pause}  Uh, at      603
  this point, I-- My sort of experience   604
  is that, um, perhaps because, uh--What  605
  do I want to say-- Uh, I sort of--      606
  Sort of felt in more recent times       607
  that, uh-- I'm too old and too poor     608
```

and not attractive enough to have 609
any-- Anybody really be interested in 610
me that way. 611
I: Uh-huh. [Hmmm.] 613

P: [And], uh, I wouldn't say I'm-- I'm 615
totally content with that. 616
I: Right. 618
P: Uh, but it's, uh-- It's not sort of 620
uh-- It's not something that I had 621
really-- Really focused on, 622
I: Uh-huh. 624
P: a lot at this point in my life. 626

---

## Data Extract 30

P: The best I can. Some-- Well, one of 240
the things-- and I'm lucky in this-- I 241
have a wife that's very understanding, 242
and been with me all through this, 243
from the beginning to the end. And we 244
do have talks, and we do have crying 245
spells, that I get down on myself, and 246
she's there to pick me up. And I 247
guess if I had a type of woman that 248
was a little different, I don't know 249
what I would do. Because it's very 250
devastating when you know that you 251
don't have nothing to offer no other 252
woman if this one leaves, if you hear 253
what I mean. 254
I: Yes. 256
P: So that's one of things that you're 258
always thinking about: What if? If I 259
wasn't with this person, what would I 260
do? How would I function? And I know 261
people say, "Well, sex ain't 262
everything." Well, they're the ones 263
that are having it. 264

---

## Data Extract 31

And a lot of times, she tells 367
me, "You know, you don't have to have 368
sex. You can be lovey-dovey." But 369
one goes with the other one, with me. 370
You just ain't got that drive. The 371
other part just don't come to me. 372
Just like having a sandwich without 373
meat. 374
I: Yes, I hear you. So she says it's 376
all right, and you can still cuddle, 377
but that's not where you want to go. 378
P: No, not at all. Not at all. 380
I: Do you think that's affecting your 382
relationship with your wife beyond 383
that? I mean, are you a little more 384
aloof from her in general? 385

P: Right, yes, I am. I am. A lot of times, we take-- I know when she gets in the mood like that, I might make sure that I stay downstairs a lot longer. Hopefully she'll go to sleep or something. I don't want to confront her. I don't even want to get into it. I don't even want to talk about it. And a lot of times, it's not fair to her. And I realize it, but then I'm caught in a dilemma of, hey, if you don't have an appetite, you can't eat. And trying to fake it just don't work neither. So I know what I'm doing, and I know why I'm doing it, and I know what caused it, the problems that it causes, but sometimes I just cant help it. Sometimes I just have to say plain, "I'm just not plain in the mood. Don't do it. Don't touch me." And this makes her become withdrawn a lot of the time.

Sexual dysfunction had another interpersonal ramification. It could mean that future prospects were limited. The potential for intimacy became a source of distress.

Data Extract 32

How can you-- you, you're conscious that you come into con-- you're going to come into contact with the opposite sex and, uh, things are probably going to be different. How much different the, the, the prostate is causing as opposed to the age, I, I don't have an answer to that. All I know is before the prostate cancer, I didn't have a problem.

I: Yeah.

P: But the-- With the, you know, women. And, and now I do. And I really can't say I do because my wife passed away a few years ago and I really haven't subjected myself to being intimate, you know. So I really don't know. All I know is I don't feel the way I used to when I run into women now. I don't have that, uh, let's experiment that I had before. Let's see what she's all about. Uh, let me see how she's talking. Uh, maybe I'll ask her to go to dinner. I, I, I know that that's been-- is a direct effect I believe of this prostate business. Because I've never been shy, so to speak, in my life. And, uh, I don't know. I don't know whether I'm just giving it up or whether, uh, whether I'm being stupid enough to, to just

```
  say, well, maybe I'm conveniently          178
  saying, well, I'm 71, it's over            179
  anyone.  Yeah.                             180
I:  Yeah.                                    182      $
P:  I'm sure ten years ago, if we had        184
  this conversation, I'd be throwing you     185
  out that window about what the hell is     186
  going on.  Why can't I get, uh, why        187
  can't I have an erection, why-- why        188
  don't I feel the same, uh, things I        189
  used to feel around, uh, the opposite      190
  sex.  But, uh, now I just, like I          191
  said, I think it's more convenient for     192
  me to just say, oh, the hell, I'm 71.      193
  Uh, what do you do?  I mean, years ago     194
  I went to-- you know, I thought of         195
  going to Niagara Falls.  Now the best      196
  I could do is go to Viagra Falls.  And     197
  I'm not going to Viagra Falls.  My--       198
  my {inaudible} is long enough and          199
  really I don't have the drive or the       200
  mental, uh, ambitions that I had           201
  before, the concerns.  I just don't. I     202
  feel that, that, uh, the prostate          203
  problems are involved because I have       204
  too many friends my age that don't         205
  have prostate problems that I can't        206
  catch up with them on payday, on check     207
  day.  So I know that alone-- maybe not     208
  alone, but I'm one of a few that's,        209
  uh, that's not chasing.  And I can         210
  think I can directly, um, you know,        211
  state that as a result of the prostate     212
  problems, radiation, and God knows         213
  what else.                                 214
```

*Interpersonal: disclosure.* Our interviews with these men revealed that men often do not feel comfortable talking about their sexuality. Sex was not only an intimate practice, but a private matter. Disclosure was typically avoided. This was even true in discussions with physicians before and long after treatment, when the consequences of treatment would have been salient issues.

Data Extract 33

```
I:    And {pause} hopefully we'll learn    707
  something that might help patients in    708
  the future                               709
P: [Yeah.]                                 711
I:    [get] a better idea about what       713
  they're getting into, and also help      714
  doctors help them through the process.   715
P:  Well, I don't really remember, uh,     717
  specifically anything that, uh, Name     718
  said about, uh, reduced sex-- Sex        719
  life.  I don't know whether he           720
  discussed that or not.  I really,        721
  really don't remember.  I-- I had--      722
  I-- With, uh, my primary urologist,      723
  uh, Dr. Name I, uh, I told him, you      724
```

know, discussed the fact that I was having an erection problem. And he, uh, said, "Well, we'll try Viagra."

Data Extract 34

BB: Right. He talked to you about the problems of the urinary problems or the sexual problems?
P: No, I didn't really get into that too much. [Uh]

---

Data Extract 35

P: And, uh, uh, I-I-- The thing is that, uh, I-- I-- I would have thought that I'd be less of a man.
BB: Mm-hmm
P: I don't mean that in a-- I don't--It's awful hard to express.
BB: No, that's okay.
P: [That's-- That's, uh--]
BB: [You're doing fine.]
P: That's just my feeling. And another thing, too, is that, uh, maybe I don't have friendships like a lot of people. But any men and women I know, I never talk this deeply with.
BB: Right.
P: In fact, I've never said that to anybody except to you today.

Data Extract 36

I: Ever talk with your wife about it?
P: {pause} Oh, well, she understands it, uh. You know.
I: Mm-hmm
P: Oh, yes. Indirectly. We-we don't-- You know, it'd be a 30 second or a minute and a half conversation [on this.]

---

Data Extract 37

P: Yes, most males-- I'm 59, almost 60. And a lot of them want to claim that they're just as good as they were when they were 20, which I know is not true. A lot of them have got high blood pressure and diabetes. Definitely got diabetes, a lot of my buddies. And so I know they're not performing. But that's beside the point. It's not something that you can talk with with a lot of other

males. They don't want to go into that.

I: Men don't want to talk about what doesn't work.

P: No, right. And black males are definitely-- It's a taboo subject, almost, in a lot of instances.

I: When you say that, you say it's a black male thing, what's up with that?

P: Well, that's one of the things that they have, that they're supposed to be good in the bed. When you lose that, then you ain't got nothing. Sex is about one of the freest things you can have. Anybody can do it. You don't have to be good at it, but you can do it. And when you lose that, then you've lost everything. Unfortunately, a lot of males determine their malehood by whether they can get it up or not.

I: When guys are talking about sex, I can imagine the kind of conversations that go on. When they're having these kind of conversations, these 59- and 60-year old men are making these kinds of claims, how do you feel when those conversations are going on? How do you act? You just sort of get quiet?

P: You got it right. You either get quiet or lie. Get quiet or lie. But you know, most people say, "Billy, I never hear you going out. I never see you doing nothing. You're always with your wife." Which, I mostly always am with my wife. There's no need to go out. I'm not going to do anything. Can't do nothing if I did. And it's not just something that you want everybody to know about. And it's just one of those things. Males sit around and talk. You either listen, or you just don't join in, or you just don't have opinions. You can just kind of keep yourself to the side. Some people always want to do more talking than you anyway, and you just let them.

I: I got you.

P: But it makes-- You know, that's another time that you think about it that maybe you don't want to think about it. Then you kind of find a place-- "Well, damn, I got an appointment. I got someplace to go." And you just kind of move yourself out of the situation.

---

Data Extract 38

```
I:    But how do you feel about all of   1178
  that?  How do you feel about your      1179
  erections?                             1180
P:  Well, disappointing.  That was one   1182
  of the pleasures of life and, uh, uh,  1183
  but, uh, it's missed.  Uh--  {pause}   1184
  I-{pause}  One of the reasons for,uh,  1185
  existing, I guess.  Proliferate and    1186
  now that-that's gone.  I'm-I'm over    1187
  the hill, I'm-{laugh} It-It's kind of  1188
  depressing.                            1189
I:    Yeah.  I-- I get that sense.       1191
  That's why I'm asking you about it     1192
  ever so gingerly.                      1193
P:  Yeah well,that's okay.  You don't    1195
  have to mince the words.               1196
I:   [Well]                              1198
P: [I'll] answer the best way I can.     1200
I:   Let me call them up.  How           1202
  depressing is it?                      1203
P:  Uh, well, it's like, uh, losing part 1205
  of your manhood.  You know, Uh, a      1206
  macho [thing.]                         1207
I:    [Mm-hmm]                           1209
P:  That along with the fact that I'm    1211
  getting older, uh, can't do the things 1212
  I used to do.  Physically.  Uh, part   1213
  of the aging process I guess.  Reach a 1214
  point where you start deteriorating.   1215
  {pause} You just have to-- You keep,   1216
  uh, rolling along, you know            1217
------------------------
```

Data Extract 39

```
P:  I'm doing what I'm supposed to do,   1407
  but, you know, I do all-- everything   1408
  that I'm going to do, that a man's     1409
  supposed to do.  I plant a garden and  1410
  do-- tending that and all that.  Take  1411
  the trash out and all that.            1412
I:   Yeah.                               1414
P: I do everything like that.  Taking    1416
  her to where she want to go.  But      1417
  otherwise, it just kills-- Uh it takes 1418
  the sex out of your life.              1419
I:    Yeah.                              1421
P:  In a man, that's-- that's, that's    1423
  uh, viable and no sex, it's, it's      1424
  nothing to it.  There's nothing to it. 1425
   So what the hell is it like--nothing. 1426
   In other words, you don't get a       1427
  cookie at the end of the day.  {laugh} 1428
  That's it.                             1429
```

***Social Context***

Men's stories about prostate cancer extended far beyond their own physical function or health. Their prostate cancer stories include many aspects of their social world, whether it be in

regards to decision making, going through treatment, or coping with side effects. The social world brought to bear included their intimate partner, family, friends, different members of the medical world and he doctors who treated them and see them for follow-up for prostate cancer. Further included were discussions about public discourse about prostate cancer (i.e. the newspaper reports, internet, and magazine articles) and men's spiritual or religious worlds. I will focus here on the how men portrayed the medical world and their doctors in relationship to their prostate cancer experiences.

Three dimensions were identified in regards to the ways men saw the medical world:

1) *Familiarity vs. Strangeness* – this captures differences in knowledge and familiarity with the medical world, including doctors and hospitals. That is for some men, the medical world was something they knew, they understood how it worked. This may have been because of past experience or because of professional experience. For others, entering into the medical world is like entering into a different culture, with a foreign language, set of rules and way of functioning.
2) *Trustworthy vs. suspect* – this captures differences in how men viewed the medical establishment as either "something noble and to be trusted" as opposed to something to be skeptical of . Some men inherently trusted the medical world to do what was best, while others were more skeptical of the motives of physicians and hospitals, insurances and health plans.
3) *Patient focused vs. professional focused* – this captures differences in the benevolence of the medical establishment. Is it in the best interest of the patient or is it mostly bureaucratic or businesslike or even dehumanizing. Issues of good vs. poor communication were also noted, with some men complaining that their physicians never warned them of the potential side effects, or that their physicians were unsympathetic to the problems they faced post treatment. Others were more satisfied with their physicians' communication, saying that they were able to work with their physicians to manage both the cancer and the treatment side effects

In addition we examined segments referring to doctors specific to the man's prostate cancer care. Here we identified 8 different roles that patients ascribed to the doctors they worked with:

1) *Discoverer:* The doctor as one who discovers the cancer, discloses the diagnosis, delivers the news, performs the PSA or biopsy and discloses the results.
2) *Informant:* The doctor is one who is responsible for providing information and explanations, and presents the alternatives and their implications.
3) *Reference link:* The doctor is a gatekeeper, facilitator of referrals to others
4) *Guider:* the doctor points the way towards sources of information and provides guidance as to what one should do. He may further dictate or direct what the man should do.
5) *Ratifier:* The doctor ratifies the patients' choice of treatment; provides authoritative sanction
6) *Supporter:* The doctor provides emotional support and reassurance.
7) *Provider:* The doctor is merely the provider of treatment services
8) *Collaborator:* The doctor is a partner, helping the man make decisions, working with the man to deal with treatment side effects.

As men presented their accounts, most included some aspect of those in the medical world they encountered, both in regards to prostate cancer, as well as in other medical encounters.

These perspectives on physicians and the medical world varied and the ways in which they portrayed the roles of their physicians may be of particular interest when considering issues of joint decision making.

***Identity***

We identified segments in which men discussed issues of masculinity, of their identities as workers or professionals, as family men and breadwinners, as well as segments in which they identified issues of feeling that they had changed since they had been diagnosed and treated. Many of the issues discussed surrounded concerns about men's sense of being a man in the face of the lack of control associated with urinary incontinence and the inability to engage in sexual activity in the way they had in the past. For example, a 72 year old white married an who had undergone prostatectomy explained how both erectile and urinary problem affected his sense of himself as a man:

> Man: Yes, but I mean it's not so much the incontinence, but I now don't stand when I go to the bathroom. I go to the bathroom like a woman does because you know, I can't zip down my pants. I've got Depends, I've got a clamp and all that, so I always have to look for a stall.
> I: Did sitting feel funny to you?
> Man: It did at first. I mean, at first everything-- You know, I thought I've lost my manhood. You know, I can't get an erection, I can't-- And this-- ... So, uh, I don't enjoy it. I'd give anything if I wasn't, but you know, I can-- As Dr. Jones said, your quality of life isn't bad. Well, I guess it isn't bad. But, uh, he doesn't know what I've done to make it not so bad. Nobody would understand it until they went through it.

In this segment, this man clearly identifies both the erectile dysfunction and the activities he needs to engage in to manage his incontinence as challenging his sense of masculinity.

Other men also discussed the impact of these problems on their masculinity. In their discussions they often sought ways to display themselves as 'men' to the interviewer. They relied not only on being able to have sex, or control their urine for their sense of identities, but in the face of these challenges to their masculine identities, men often discussed other valued masculine identities and valued life identities. In their presentation of themselves, men presented themselves as successfully maintaining a masculine and cogent self, despite the infelicities presented by the cancer treatment. Thus men presented themselves as professionals or workers, breadwinners, family men, providers for their families, active in their communities, and as good husbands.

This aspect of men's experience with prostate cancer is crucial for understanding what it might mean for someone to be a prostate cancer survivor. While some men explicitly discussed being 'a survivor,' others implicitly revealed the ways in which they are moving forward in their lives. It may be that good survivor care not only focuses on remediation of the failings of the body, but refocusing men on aspects of themselves that help them maintain their sense of self in the face of challenges.

**Profiles of Decision Making**

Treatment decisions are turning points in the lives of men with early prostate cancer. Our analysis of the components of men's' narrative accounts defined several components of decision

making. In this section, we expand that analysis by characterizing eight general profiles of decision making stories. We draw upon the combined retrospective interviews conducted in accomplishing Tasks 1 and 2. That is, we include a diverse set of interviews conducted with men who received care in two VA medical centers, a multispecialty group practice in Greater Boston, and the long term (4 to 8 years) survivors who recruited when they sought consultation about treatment at a cancer center and related, Harvard-affiliated hospitals in Boston.

- Passages of interviews in which the men provided accounts of their treatment decisions, that is, they described the choices they made, how they reached those decisions, what they considered, who they consulted, and how they felt about their choices "at the time" and "now" as they looked back, (coded as *Decision*) were extracted from 61 interviews. Most of the interviews contained multiple passages identified as "Decision." These passages were reduced to 61 précis to capture the gist, tone, and salient points of each, albeit through a rather impressionistic reading. Decision passages from three interviews were not reduced in this way. Two were too brief to characterize. One was largely an account provided by the man's wife, who had participated substantially in the interview, reducing its comparability to the first person accounts provided in most of the interviews.
- The précis represent the men's narratives of their treatment decisions that they told over the course of their respective interviews.
- The précis were then marked by the man's ordinal score (i.e., high, moderate or low) on the Decision Confidence scale (i.e., Informed Decision), obtained from the survey data. Three précis could not be marked because of missing data for this scale. The précis, marked in this way, were then sorted by level of decision confidence.
- Sorted in this way, a pattern of thematic similarities became apparent. The pattern relates to representations of agency and responsibility for the decisions and the framing of trades between cure/control and costs/side effects. The pattern suggests eleven profiles of accounts.

Eleven Decision Profiles

1. I followed the doctor

Seven men told stories of following their doctor's lead in deciding which treatment to pursue. Four chose EBRT and three chose RP, although one of the men who opted for RP delayed a decision and watched as long as he could until heeding his doctor's indication that it was time to do something. Six expressed high confidence, while one had a moderate score on the Informed Decision scale.

Following the doctor entailed a compliant orientation. These men looked to their doctors to be told what to do and then did what was told. They reported this orientation without misgivings. It was the reasonable and appropriate response to the diagnosis of cancer. However, two (11, 19) indicated they waited or wanted to wait as long as they could, until doing what their doctors said they should do. One of these (11) was active in pursuing opinions and information, until deciding in a way consistent with his doctors' lead. Conversely, one (7) felt urgency to follow his doctor's advice to undergo RP as quickly as possible. Two men (1, 2) noted their ignorance of the medical issues, which motivated their reliance on their doctors; one (2) also

relied on his daughter who worked at a hospital and had her own experience with skin cancer, and thus knew the questions to ask the doctor and facilitate his guidance, leading to undergoing EBRT with the same doctor who had treated her skin cancer. Two men minimized their own agency, with one indicating that he simply pursued the EBRT that his doctors said they would try first. The other, a 78 year old man who expressed only moderate confidence, reported asking the iconic question of his doctor: "If I were your father, what would you say?"

Examples of Profile 1: #19 and #2

**[19] 2-4274: age ?, Watch → RP Decision Confidence: High**

**Watched as long as I could; told might have to act eventually; took doctor's recommendation for surgery when it was time; failure to act when it's time is fatal**

The next time the PSA was up higher.
So the doctor said I should have something done.
So I went in and had the operation.
He told me beforehand what might happen.
What could I say?
Anyway, that was it.
Not good with discussion of alternatives.
He discussed it with myself and my wife
We felt that was the best way to go.
I had a friend of mine that didn't do it at first and the cancer spread.
Next thing I know he was gone.

**[2] 1100340R: age 77, EBRT Decision Confidence: High**

**They recommended the radiation, said I should be fine; daughter knew the questions to ask; she'd had cancerous spot on her shoulder said her radiation doctor was the best.**

Dr. Brenner didn't talk much of other options.
They did recommend the radiation, that I do the radiation, it should be fine.
I myself said no operation.
My daughter-in-law, a lab tech at *Name* Memorial Hospital, is my confidante.
She recommended what to do.
She knew Dr. Brenner, she talked with him, and she said no operation.
She said I don't think you should do it, it's quite a deal, so I went with the radiation.
She knew the questions to ask.
What happened was, she had a spot on her shoulder that was cancerous and she had the radiology treatment, and she went to Dr. *Name*, she's a woman doctor, and she says that's the doctor you want for your radiology.

2. I followed the doctor, with some diffidence

Three men told stories of compliantly following their doctor's lead, but added notes of misgivings that contrasted with the largely confident reliance on the doctor characterizing the first type of account. Two of these (50, 51) had low decision confidence scores. One (50)

lamented making a rash decision to accede to his doctor's recommendation to undergo EBRT. He reproached himself for going along with radiation too quickly and not getting additional opinions, later attributing problems with diabetes to his radiation therapy. Another (51) man said he was befuddled by the choice of treatments and so he went along with the recommendation for RP, yet complained that doctors did not give him enough clear and accurate information. The account describes a crisis situation, with a brother who was dying of prostate cancer at the time and a radiation doctor who he did not like. While his urologist told him he would be doing the right thing by getting the surgery, and he feels he did nip it in the bud, he nonetheless suffers the consequences of incontinence and impotence, for which he blames himself. Finally, a third (37) compliance account describes being frightened and giving up in the face of the diagnosis and decision. With some regret that he should have explored more options, he chose to trust the medical system and chance by being "flipped" by the PIVOT trial to undergo surgery.

Example of Profile 2: #51

**[51] 1101840: age 67, RP Decision Confidence: Low**

**Befuddled, failed to research options, just went along; but said get it done; but doctors don't say enough about the risks, figures are nonsense, wrong, too little information; doctors manipulate. Doctor told me I'd be *doing the right thing* if I had surgery. Disliked radiation doctor. Brother dying of prostate cancer at the time.**
**Nipped it in the bud; happy, except for the incontinence and the impotence**
**Blame Self**

While all this was going on, I was diagnosed
And *I really didn't look into it*
I was all befuddled
I just went right along
I said, okay, get it done, get it out
I might have opted for other things now,
It's great to second guess at myself
The high priority item for the doctors is to get the cancer out
And he did that
You don't get enough information from the doctors when they first diagnose you
They don't give you enough information about the impotence, the incontinence
They quote all these figures and its just a lot of nonsense as far as I'm concerned.
And most of them are wrong
But I go to the session where it's for prostate people and everybody comes out is impotent
It's the rare bird that has it, even with the nerve sparing stuff
There is some success but not as much as they pump it up to be
I think they undersell the man
I think they think the man would not opt for surgery with all these things facing him, you know, impotence
When they're telling you 40% are going to be impotent, it's probably 80%
I feel like the lamb being led to slaughter
If I tell the truth he won't have the judgment to have the surgery, he might go and have radiation
There seems to be the underlying competitiveness between surgeons and radiologists
I was in an emotional state because of my brother

I was kind of up in the air
Penile implant may have been mentioned, but it wasn't encouraged
From the get-go I made up my mind to have surgery
Surgery would be the surest and cleanest way out of this than the radiation
I'm happy for the results, except for the incontinence and the impotence
Spoke to an oncologist at Kenmore, he recommended surgery
I'd be doing the right thing if I had surgery
Just nip this thing in the bud
Talked to a radiation oncologist, didn't like him.
Talked about me, but not to me.
Didn't even get undressed.
Brother was dying of prostate cancer at the time
He didn't live long after he was diagnosed

3. I sought to cure the cancer

Eleven accounts are focused on deciding an approach to treatment in order to cure the cancer. That is, they are focused on accomplishing the primary, intended effect of treatment. Nine maintain this focus while also acknowledging the possibility of secondary, unintended side effects of treatment. In addition, nine are presented by men who scored high on decision confidence, while one was moderate and one was low.

In two accounts (26, 27), cure is the only significant issue. One wanted to get the cancer out of there, the other stressed certainty of cure and the fact that radiation would offer no fall back option if it failed. Both chose RP. Both had consulted doctors at Hospital, who had agreed that RP was the way to go. Both reported high decision confidence.

In two other accounts (5, 22), side effects are acknowledged, but they are presented as posing little to no risk to distract from the pursuit of cure. In 5, the man complained that he had to make the decision on his own, as he expected qualified professionals to decide an issue outside of his own expertise as an engineer. Yet, by his calculation and based on his reading, including Partin tables, he anticipated an 80% chance of coming out clean after surgery, with no side effects. While confident of his decision, he was unhappy with the resulting urinary and sexual dysfunction, which he attributed to poor surgical performance, not his choice. In 22, the gold standard was chosen, along with a highly experienced surgeon who carried a low risk of incontinence.

Account 44 is slightly different from 5 and 22. Side effects are acknowledged as a risk of pursuing cure, but the man expressed less certainty that they would be avoided. Told it was his decision, he consulted doctors at *Hospital* and *Hospital*, decided to pursue RP, and then sought care from Walsh to reduce his risk of sexual dysfunction, *hoping* for the best. His decision confidence was moderate.

Five were focused on curing the cancer, while acknowledging the substantial risks of side effects. All five were highly confident of their decisions. Cure overrode the risks. All chose RP, going forward with aggressive treatment and expressing something of a damn the torpedoes attitude. For one (25), the attitude was not so brave as an acknowledgement that the whole matter of cancer treatment was unpleasant (I get squeamish). While going forward with RP carried risks, it also carried the possibility of eliminating the whole problem quickly and finally. Two (12, 3) appeared to hope for the best that they'd avoid side effects while focused on the

likelihood of eliminating the cancer. One (4) noted that side effects mattered little compared with getting rid of the cancer, since the cancer would kill if not eliminated.

Finally, one account (54) is a hero's story of sacrifice—willingness to sacrifice potency and continence in order to cure the cancer. Side effects are somewhat more certain, but death from uncontrolled cancer is quite certain. A vivid analogy is presented: "Look at that guy who fell on the mountain and got his arm caught and had to cut his arm off." Yet, in contrast with the others who told stories of this type, this man reported low decision confidence.

Examples of Profile 3: #27 and #25

**[27] 2-6107: age 64, RP Decision Confidence: High**

**At the end of the day, the specialists at *Hospital* boiled it down in favor of prostatectomy; other approaches were iffy, no fall back if radiation failed**

When Dr. *Name* made his diagnosis, I decided that I wanted somebody else's opinion too, seeing it was an operation of this magnitude that I should do that. So I went up to Boston, *Hospital.*
Spent the day there, battery of tests. One fellow said radiation, another said operation. One said plant the seeds. At the end of the day I spoke with the head man and boiled it down and it was pretty obvious that prostatectomy was the most efficient way of dealing with it. So with that endorsement I returned to Providence to make plans to have it done here.
The other treatments were iffy.
I didn't like the fact that if they gave me radiation that it might work, but down the road, if I had a problem, and they had to operate, it would be very difficult or impossible because of the radiation destroying the tissue.
The pellets was in its infancy.
Wife went with me; she's an intelligent lady.
Helpful to talk to other men early on. Kind of gave me confidence, courage, so I became more familiar with what's going to happen. Made it easier.

**[25] 2-4563: age 69, RP Decision Confidence: High**

**Rejected advice to get chemo and radiation; went to best doctor who could remove it 100%, despite warning of risks to sex life; wanted to do it and forget about cancer; I get squeamish, driven to get rid of problem altogether.**

Doctor I go to doesn't do operations, so he sent me to his associate.
And he checked me and said, yes, you're starting to get prostate cancer
I would suggest you take radiation or chemo or whatever they want to do
I went back to my internist
I'm not too happy with that.
I'm 69 and not quite ready to take 8 or 10 years of chemo
Well, I went to Boston and saw the doctor there
And he agreed with what I said
Let's take it out completely
Which I did
And he explained all the ramifications, what will happen with my sex life, what could happen, and it worked out fine
The associate said it was a slow moving thing, and with chemo, no problems until you're 80

That's when I went to Boston to talk with one of the best doctors in the world.
Got a report, the 400 best doctors in the country, he was one of them
Dr. Richie
Doctor who offered chemo could not assure me that this would stop it 100%
When I hear cancer, I get squeamish
Since then have known of younger men who had the start of prostate cancer and got the chemo and they're doing okay
So this doctor may have been on the ball too.
Went to Richie.
I didn't even mention to him that that's (surgery) is what I wanted. I just let him check me over and I asked him what he thought. He said, if I were you, I'd have it removed 100% and you won't have any problems anymore. He did tell me the ramifications of it so I had no surprises.
The ramifications were that the sex life would probably be gone, although they were working on different things to make it work.
*What was going through your mind at that time, 7 years ago, when he's telling you, "We can cut it out, but your sex life's going to be gone?*
I said to myself, what's more important to me? Sex life at this time more important to me than a clear mind that I don't worry about cancer coming back? It's just one of those things that hit me, and I think I had to take what's best for me in my own mind. At that time, the best thing to do was to remove it and I wouldn't have to worry about it. If anything came about that would restore my sex life, I was ahead of the game. If not, well, I had to take my chances with it.
Wife and I talked it over, peace of mind was very important to us.
She's 7 years younger, in her prime, and I didn't want to deprive her of this so-called pleasure.
The 8 or 9 years indicated by first doctor, who said surgery wasn't necessary, was insufficient.
Thought I'd outlive that.
I wanted it to be stress free. I didn't want them to say when I'm 78 years old, I think we've got to remove your prostate.
I'm one of the squeamish guys. Let's do it all now and forget about it.
As long as my wife went along with it, that took care of the battle.

4. Went forward with trepidation.

Four accounts described confusion, uncertainty, and indecisiveness before pushing forward with RP and some anxiety. Three were moderate and one was low on decision confidence. Collecting and making sense of information and multiple opinions was difficult. One (29) oscillated between a urologist (Richie) who offered a certain remedy and Man-to-Man groups, which stirred doubt. Another (56 and low decision confidence) was relieved when *Doctor* at *Hospital* took him under his wing and directed him to urologist and radiation oncologist who happily agreed on RP, although his final decision was "primitive" and informed by wish to just get it out of his body.

Example of Profile 4: #56

**[56] 2-6349: age 58, RP Decision Confidence: Low**

**GP recommended seeds, easy, be done; then collected expert opinions; taken under wing by *Doctor* at *Hospital*; urologist and radiation doctor both recommended surgery; in the end, not rational, but wishful: close your eyes, trust, hope for the best, and take a dive**

**So taking their advice, mulling it over, wife and I *decided on primitive basis* for surgery; get it out of your body**
**So I was scheduled in July with great trepidation**

Mantra then was we caught it early, that's great. What's difficult is choosing from all the great options.
My general practitioner was high on the seeds: just go in, have it done, outpatient, flying free from that point on.
So started reading and visiting chat rooms
When we saw *Doctor* he said he can't advise you on whether surgery or radiation, but he recommended hormonal therapy with either
But I read that was controversial, side effects
Then saw radiologist
Then got recommendation to see *Doctor* at *Hospital*, through my wife's therapist.
And he was a total diversion from some of the other people we'd seen
First, he seemed to be very concerned with championing the patient, really taking the patient under his wing and making sure whoever the patient talked to was top of his field
Sent to *Doctor*, chair of urology at *Hospital*, who said you don't want that hormone therapy: nothing proven, no indications it would benefit you.
Then a South African radiologist with wonderful bedside manner.
He recommended surgery.
So taking their advice, mulling it over, wife and I decided on primitive basis for surgery; get it out of your body
So I was scheduled in July with great trepidation

5. Went forward with resignation.

Four accounts convey resignation, laced with depression. Two chose RP and two chose EBRT. Three reported moderate decision confidence, one was low. One (36) told his doctor just to take it out. There was no concern about saving erectile function since he wasn't getting any sex anyway. Another (30) opted for EBRT, thinking he would have a little bit better chance of preserving potency, but noted that neither option was good. In similar fashion, one (52) presented EBRT as minimizing the risk of added insult of ending up in diapers after cancer. Both he and 34 placed decisions in the context of dealing with the progressive insults to self esteem that come with aging and approaching mortality.

Example of Profile 5: #30

**[30] 1348470: age 57, EBRT** **Decision Confidence: Moderate**

**Resolved for surgery but really wasn't eager for the knife; radiation might leave sexual potency, but might lose it; surgery definitely lose it**
**Resignation: no good options, bodily losses, but I can deal with it; I'm still living**

I went and talked to my aunt and uncle and family and my children.
And then when I talked to the doctors, the doctor down in radiation told me it was in time and he could get rid of it.
They told me about the surgery, but they said the radiation would work instead of surgery.
I had made up my mind to have surgery, too.

But they gave me the option of surgery or radiology.
And after I talked to the doctor in radiation I went for it.
I really wasn't eager for the knife.
And the doctor in urology told me that the radiation would be a chance that I would not lose my sexual potency, but there was still a chance I would lose it.
And if I took the operation that I would lose it.
See, the operation almost guaranteed that you lose your sexual drive.
So that's why I preferred radiation.
Know that it was a possibility.
But I can deal with that because I'm still living.

6. Options were limited

Three accounts highlighted limited options. All were presented by men who pursued EBRT. In two cases (28, 45; both moderate decision confidence), surgery was excluded by age and a prior TURP, or by cardiac disease. EBRT was the only option available. In the third case (53; low decision confidence), brachytherapy was the preferred approach, after hearing of friends' experiences on the West Coast, but an MRI indicated that he would not benefit from seeds. Surgery was strongly dispreferred at the outset, since other friends had ended up in diapers after RP.

Example of Profile 6: #53

**[53] 2-4065: age 75, EBRT Decision Confidence: Low**

**Did my research.**
**Really wanted seeds; some friends got seeds on west coast, absolutely pleased; but MRI said I wouldn't benefit from seeds; wasn't for surgery at all; other friends had radiation; one friend had surgery, in terrible shape for a year, in a diaper; didn't want that**

So I did my research.
I ended up going to a couple of doctors and surgeons
And I ended up with Dr. *Name*, he's an oncologist
At the time, he was the only one who believed in hormone therapy first, then radiation, and then continue with the hormone thereafter
What I really wanted was to have the seeds
Dr. *Name* told me after the MRI that whatever the configuration of my prostate, I probably would have lost part of the seeds, I wouldn't get the full benefit
That's when I saw Dr. *Name*
I wasn't for surgery at all.
A couple of friends had gone out to the west coast to have the seeds, they were absolutely so pleased
Then three of my friends had the radiation without the hormone
*What was unpleasant about surgery?*
One of my friends had had surgery, for a year he was in terrible shape, had to wear a diaper
I just didn't want to go through it

7. EBRT works well enough, and it avoids the unpleasant side effects of RP

Three accounts describe choosing EBRT instead of RP for no strong reason, except doctors supported that choice. All three reported high decision confidence.

Example of Profile 7: #8

**[8] 1346260R: age 74, EBRT Decision Confidence: High**

It went up to cancer.
And that's when they told me I had an option of either getting an operation or I could go ahead on for radiation.
I was about 70 something, 71, 72. I'm 75 now.

8. EBRT avoids the side effects of RP

Ten accounts present EBRT being pursued instead of RP because it avoids the unpleasant effects that may accompany RP. Four of these are given by men with high decision confidence; five are from men reporting moderate confidence.

Two (15, 20) who reported high confidence indicated that they had considered RP but had doubted the claims of surgeons who may have oversold the advantages (and understated the risks) of RP. In contrast, three (31, 32, 33; moderately confident) said they chose EBRT in order to avoid the aggressive, invasive approach of RP and its awful side effects. One (31) was relieved when he learned that he need not undergo surgery—a possibility that evoked fear as soon as he learned the diagnosis. In this case, compliance with the doctor allowed avoidance of dreaded treatment. In similar fashion, 32 and 33 were happy to avoid a treatment that might leave them impotent or in diapers.

Example of Profile 8: #32

**[32] 1100260R: age 71, EBRT Decision Confidence: Moderate**

**Avoidance of complete operation—good reason to do that, but not necessary; try the less invasive, less costly alternative. Doctors and I chose radiation: acceptable, avoided invasive surgery and its side effects, though I was *no longer sexually attractive***
**Rationalization of choice of non-aggressive strategy**

We talked about options for treatment,
and sort of came to conclusions jointly that we should try radiation rather than a complete operation,
that would be much more of a production
and have more side effects and so on
What was the discussion like?
Well, I didn't feel that they really pushed for any particular option.
Told that other doctors at other hospital were trying radioactive seeds, but they didn't push this.
That was the third option, aside from radiation or the full operation, or doing nothing.
Decided early on to go with radiation, why?

It was the description of all that would be involved in the operation and the amount of recovery, and some of the possible side effects.
There was no good reason to do that; it didn't seem to be necessary
What side effects were troublesome?
Well one was difficulties with urination
*There was, of course, a matter of perhaps an effect on sexual ability; but I don't' know how much I thought about that, really.*
For one thing, I *wasn't married* at this point; divorced twice.
I had had *three children* with the first wife of 19 years.
Three years later married second wife, who had *two children.*
And we didn't have more children while we were married.
In recent times, feel I'm too old, too poor, and not attractive enough to have anybody interested in me in that way
So it's not something I focused on.

9. Brachytherapy avoided the side effects of RP

Four accounts described decisions to pursue brachytherapy because it avoided the unpleasant side effects of RP. Two were presented by men who expressed high confidence in their decisions. One (23) confidently chose seeds after understanding that prostate cancer was not going to kill him, thus reducing the need for an invasive course of treatment. Another (16) indicated that his uncertainty about the efficacy of brachytherapy was remedied by the certain authority of Dr. *Name*. The other two expressed moderate confidence. One (42) wanted to avoid cutting of the urethra and attendant risk of incontinence, yet characterized Korda as a crybaby for complaining about these outcomes. The other leaned on Andy Grove's account to counter the aggressive pitches of urologists who offered cure accompanied by risks of diapers.

Examples of Profile 9: #23 and #42

**[23] 2-4485: age 67, BrachytherapyDecision Confidence: High**

**Learned cancer wouldn't kill me so chose least invasive course: MRI seeds, convenient, less incontinence, less impotence. But can't just watch and wait; walk around with cancer and worry, and cancer grows and kills you.**

Saw nine different doctors, then the last guy.
Asked him, if you want to live to 90, which procedure do you recommend?
He said something else than the cancer would kill you.
So wife and I decided on least invasive course.
Had been intrigued by seeds from the beginning, especially as I learned what the alternatives were
Especially after meeting Dr *Name*; really impressed with him, thought the MRI placement much better than ultrasound
Got better coverage than with ultrasound
All the surgeons said operate and all the radiologists said you have a choice
Since I knew it was not something that had to be treated the next day, did a lot of reading and surprised myself
Survival numbers were questionable since most patients were older and would die of something else

Decided on basis of less invasive, shorter recovery, less chance of incontinence and impotence. No watch and wait: why walk around with cancer inside of you? Then you would worry. Was it going to grow? My father-in-law died of prostate cancer.

**[42] 1101400: age 66, brachytherapy** **Decision Confidence: Moderate**

**Many doctors, many books, dead set against surgery: not that serious, cutting the urethra, impotence; internal was four hour and then home, walking the dog; yet, Korda's complaints about surgery made him a crybaby**

The doctor explained that the doubling in a short time was not so good.
And they always find that the biopsy after surgery shows more cancer than the six needles show.
And they went through all the options: surgical, external radiation, internal radiation, do nothing.
And they arranged for me to have a discussion with the fellow at Kenmore Square, explained all the options.
And they said you should go visit each of these persons and the options.
Which I did.
There were many books in the library: 10, 20, an infinite number, which I read most.
And I chose the internal radiation.
Thought it was the least side effects, and the easiest, compared to the surgical, external
The surgical I was absolutely against.
I didn't think that was serious; I mean I didn't have a PSA of 80
And the fear of cutting the urethra to the bladder, resealing that thing
Plus all the other side effects
Internal was four hours, I was home the next morning walking the dog
Had plenty of time, four, five months.
Doctors at Harvard Health were very good.
One in particular, when out of his way to explain everything.
*Did they leave it totally up to you?*
It has to be, unless you're seriously ill.
*Was chance of impotence a factor?*
Yes, I thought the internal was the least.
Wife was dead set against the operation.
We read the book by editor at Scribner [Korda], describing an awful experience.
I think he was a bit of a cry baby.

10. Brachytherapy was least drastic approach to dealing with prostate cancer

Instead of the avoidance of side effects, these three accounts highlighted RP as an extreme measure, involving lengthy recovery, and barbarously invasive surgery, all of which could be avoided by a relatively simple, modern procedure. One wanted to get the cancer out with the least downtime. Another was relieved to find an alternative to the barbaric gold standard of RP. A third, who reported low confidence, was quite ambivalent about treatment. He could have convinced himself to do nothing at all, but his wife favored an active response. Seeds were the compromise solution. However, he also noted that fluctuating PSA values since treatment leave him uncertain about effectiveness of treatment and even its necessity.

Example of Profile 10: #18

**[18] 2-4219: age 60, BrachytherapyDecision Confidence: High**

**Big shock, but learned I had time, learned that gold standard is oversold, old fashioned, barbaric; found seeds and clinical trial of MRI; given uncertainty, why opt for the most drastic**

Doctor tells you that you have the Big C.
Right from the beginning, it's confusing.
The urologist said it's almost certainly confined to the prostate.
This is the surgeon, the guy who can sort of deal with this.
But you're already thrown into this a few steps down the line.
So it's like, okay, you've got cancer: that's the bad news.
The good news is I can deal with this, and the gold standard, the radical prostatectomy.
You're into that realm: do you want this? Nerve sparing?
And it's a little overwhelming
You've got cancer; here's an option. And it's pretty much the best option.
Doctors and friends say this is the gold standard.
So even friends who were supportive of my thinking about this were not sure about anything other than surgery.
So what I found actually helpful in my thinking was to stop, step back and really go to the beginning. There's certain characteristics of prostate cancer that allow you to do that.
If you're talking about breast cancer, you want to do something yesterday.
Prostate cancer gives you time. to really weigh the options.
So going back to the beginning, you've got cancer, do you want to do anything?
That was helpful
Once I decided that I wanted to do something, then decided what.
Went outside HVMA to see D'Amico, who was radiation oncologist, but laid out all the options.
Impressed by trial of MRI seed placement.
I liked the idea of seed therapy.
I liked the idea of being in a clinical trial.
They're interested in having a good study so they're interested in you.
Suspicious of surgery, tend to do things conservatively.
Saw surgery as old fashioned and barbaric.
Concerned about incontinence and sexual function
I didn't believe the nerve sparing stuff.
If you're really concerned about the cancer, maybe you don't really spare those nerves.
The fact that the urethra has to be severed and then sewn back together, all kinds of issues around recovery, you have a catheter for several weeks.
And you can't tell if your cancer is going to kill you. How do you figure that out?
So it seemed to me with that kind of uncertainty, why would I want to opt for the most drastic procedure for dealing with it?

11. Skeptical and resistant to active therapy

Three men told stories of skepticism and resistance to the pursuit of active therapy. All three chose watchful waiting and reported moderate or low confidence in their decisions.

Example of Profile 11

**[47] 2-4517: age 85, Watch → Hormone Decision Confidence: Moderate**

**Several opinions, including DFCI; male doctors urged action, female doctor said wait, so I did, 5 years until doctor urged action: Lupron; surgery left people screwed up, radiation not so wonderful either; wife had died after two [futile] operations for spreading bladder cancer; cure is unlikely; have to live with the possibility of disaster**

Definitely cancer, but not very large, not in motion or activity, seemed to be kind of quiet.
Doctor mentioned a number of operations: type where you remove the prostate entirely, or type where they were starting to experiment with attacking the cancer in the prostate, radiation.
Finally got smart enough to go to Boston for second opinion at Jimmy Fund, DFCI
Saw three doctors, got the impression that they operated this way, as a group.
The two men were more inclined to take some action: surgery or radiation. The woman (oncologist) was very much the opposite.
She said, absolutely, I would watch and wait.
Keep your eye on it.
Have your PSA taken periodically, and don't forget about it
Sure you could have an operation so someone could chalk up another success
She was rabid, strong feeing I should watch and wait, so that's what I did for 5, 6 years
Until three years ago.
But finally, one time, about three years ago, he said, "You know, I don't understand you, Mr. [Name]. I mean, this thing is dangerous, and threatening your life. I think you should have treatment." I was a little surprised, because he hadn't led up to it. He kind of hit me fast with it. And I said, "Well, what do you suggest?" And he said, "Well, an inoculation is the way to get that PSA down. We've got to get it down." So he put me on an inoculation in the buttocks. I wish I could name the drug for you, but you must know it. Lupron, that's it.
We argued, no discussed the effects of Lupron.
Well, there's the end of my sex life.
I was keeping company with a woman and we talked about marriage and so forth.
And I said, oh hell.
But anyway, I went along with it, because at my age, I'm 85
Back at the beginning, was never impressed with the surgical approach.
Statistics indicate that people too often impotent or screwed up in one way or another
The surgery is not an easy and sure thing, like taking out an appendix
On the other hand, radiation was not so wonderful either
I went through a period with my wife-- It took us several years to bring her to the point where she couldn't survive any longer. She had cancer of the bladder at the beginning. Then the doctor said by operation, they had removed all sign of it. But it turned out that six or eight months later, they detected some more. I think there was a second operation, and then apparently it was spreading faster than they expected, and so forth. But it does make me feel as though dealing with cancer is not quite-- It's not something that's easily isolated and taken care of, and that's the end of it. It's not like having a tooth pulled. And you know, you hear stories, and you read articles about this and that. I don't know. You say, "Well, I made my choice. I'm going to have to live by it." Although in my case, I guess I can always say that if I get the disastrous news that the cancer has spread, or I feel bad, or I have some other symptoms, I can do something about it. I can always have the operation, can I not?
Doctor suddenly argued for active treatment, after following PSA and seeing it go higher.

It struck me that he had held his opinion back for some time.
And I said what is the treatment you have in mind?
If he had said operate or radiate or chemotherapy I would not go into it easily.
But when he said injection would keep the PSA down I went for it kind of easily.
Never had a problem with needles.

| | |
|---|---|
| **Précis of Decision Making Accounts**, marked by age and treatment, and by level of decision confidence from survey responses. Initially sorted by level of decision confidence and by treatment, then sorted again by emergent themes relating to agency and framing of trades between cure/control and costs/side effects. | |
| **Followed Doctor—with Confidence** | |
| 2 | 1100340R: age 77, EBRT Decision Confidence: High<br>They recommended the radiation, said I should be fine; daughter knew the questions to ask; she'd had cancerous spot on her shoulder said her radiation doctor was the best. Led by daughter and supported by her in following doctor. |
| 1 | 1100250R: age 77, EBRT Decision Confidence: High<br>Strongly directed by doctors to the only option of radiation; didn't know myself, but confidence in doctors, trusted them |
| 9 | 1346370R: age 69, EBRT Decision Confidence: High<br>They just said we prefer radiation; we'll try that first; something else if it gets worse |
| 39 | 1240150: age 78, EBRT Decision Confidence: Moderate<br>Minimize the Whole Problem: Just wanted it taken care of. If I were your father, what would you say? and he said he'd take the radiation |
| 7 | 1240580: age 61, RP Decision Confidence: High<br>Was told I had less than a year to live, so took strong recommendations for surgery, but have learned more since; actually low numbers at diagnosis, other options; but he explained all the options to me; denied access to Roswell; we are enough doctors here. Urgency motivated compliance. Doctors demanded trust. |
| 19 | 2-4274: age ?, Watch → RP Decision Confidence: High<br>Watched as long as I could, with doctor's permission; told might have to act eventually; took doctor's recommendation for surgery when it was time; failure to act when it's time is fatal |
| 11 | 1101590R: age 66, RP Decision Confidence: High<br>Considered benign neglect, reasonable to just let it go, but rapidly rising PSA pushed me to act; learned much, chose the trauma of surgery; it was the right thing to do; acquired and read much, but discarded it when decision was behind me; doctors stepped back, left me to decide, but pointed me in the right direction |
| **Followed Doctor—with Diffidence** | |
| 37 | 1239650: age 77, RP Decision Confidence: Moderate<br>Frightened; perhaps too rash; should have explored more second opinions; opted to trust the system, be a guinea pig, and be flipped by PIVOT to surgery |
| 51 | 1101840: age 67, RP Decision Confidence: Low<br>Befuddled, failed to research options, just went along; but said get it done; but doctors don't say enough about the risks, figures are nonsense, wrong, too little information; doctors manipulate. Doctor told me I'd be *doing the right thing* if I had surgery. Disliked radiation doctor. Brother dying of prostate cancer at the time. Nipped it in the bud; happy, except for the incontinence and the impotence. Blame Self |
| 50 | 1348840R: age 79, EBRT Decision Confidence: Low<br>Attributes diabetes problems to that radiation; I should have got more options, but *went along* with radiation; I said if you can get rid of it, I'd like to do it now, and that's a bad mistake; no communication with another person like we're talking now—Rash, didn't work it through, didn't appreciate consequences for health<br>Blame Self |
| **Actively Sought to Cure the Cancer:** 26, 27, Considered options, side effects insignificant. 5, 22, Seek Cure; Expecting No Side Effects 44, Went Forward, Hoping for Best; Lost; 25, 12, 3, 4, 14, Seek Cure; Awareness of Risks of Side Effects Notwithstanding; 54, Sacrifice | |
| 26 | 2-4570: age 72, RP Decision Confidence: High<br>Wanted to get it out of there and all three doctors at *Hospital* concluded that I ought to have prostatectomy |
| 27 | 2-6107: age 64, RP Decision Confidence: High |

| | |
|---|---|
| | At the end of the day, the specialists at DFCI boiled it down in favor of prostatectomy; other approaches were iffy, no fall back if radiation failed |
| | |
| 5 | 1102420R: age 74, RP Decision Confidence: High<br>Wanted to rely on experts, but left to acquire my own expertise and make the best choice I could; ought to have surgery, get it all clear, and book said I had 80% chance to come out clean; I didn't expect to turn out incontinent and impotent<br>Made his own decision as well as he could, with diligence; unexpected outcomes responsibility of doctor's failure |
| 22 | 2-4483: age 72, RP Decision Confidence: High<br>Laid out options, got information, chose gold standard for cure and surgeon with low risk of incontinence |
| | |
| 44 | 2-4030: age 70, RP Decision Confidence: Moderate<br>Told it was my decision, got second opinions at *Hospital*, *Hospital*; given surgery, went to see Walsh, who doesn't like the name "nerve sparing," but I wasn't looking ED as a big risk |
| | |
| 25 | 2-4563: age 69, RP Decision Confidence: High<br>Rejected advice to get chemo and radiation; went to best doctor who could remove it 100%, despite warning of risks to sex life; wanted to do it and forget about cancer; I get squeamish, driven to get rid of problem altogether. |
| 12 | 1101860R: age 57, RP Decision Confidence: High<br>Many experts felt pretty sure cancer was encapsulated, so good time to hit it. First, get rid of cancer; but sex number 2. "Nerve sparing" may be bullshit, but my wife and I decided, what the hell, let's do it. |
| 3 | 1100710: age 59, RP Decision Confidence: High<br>Devastating diagnosis; just take it out, but had to work through tough decision with doctors and wife; parents, brother died of cancer; cancer can spread with surgery; resolved to hope for best with wife about sex; mostly wanted things done quickly. This therapy has left me impotent, but I'm not complaining. |
| 4 | 11001070, age 61, RP Decision Confidence: High<br>Older men don't do well with surgery, but I was young; Chose the difficult, but effective and enlightened path; main thing: get rid of the cancer, otherwise side effects don't matter because you'll die; PSA meaningful after RP, but not after radiation; RP is gold standard |
| 14 | 2-4046: age 64, RP Decision Confidence: High<br>Needed to deliberate carefully; able to do that at *Hospital*; they gave me time. Sex was an issue, but overriding concern, get rid of cancer, in spite of risks that were underestimated by chosen surgeon. Surgery removes it, radiation kills it but cells are left in your body; seeds required a trip to Seattle and had less evidence of success |
| | |
| 54 | 2-4402: age 63, EBRT Decision Confidence: Low<br>Wanted the most aggressive, but surgery ruled out after first doctor pushed for it, because of clinical fact of perineural invasion.<br>Informed of options, but also informed of limited good effects; good health was quickly circumscribed, foreclosed. Time for sacrifice for the sake of salvage. Wanted most aggressive, but *No good way forward.*<br>*Look at that guy who fell on the mountain and got his arm caught and had to cut his arm off.*<br>What are your choices? You have to make your choices with the treatments and your can weigh whether or not you can tolerate them or not, but you have to do something. If you don't do anything, forget it, you're going to die. |

| | |
|---|---|
| **Went Forward with Trepidation** | |
| 35 | 1239270: age 57; RP Decision Confidence: Moderate<br>Thought I was going to die, then rose to the challenge and made the tough decision, despite the risks; hardest part was making a decision; uneasy with threat to potency. Go forward, in uncertainty, with trepidation. |
| 41 | 1100320R: age 65, RP Decision Confidence: Moderate<br>You hope you've done the right thing, and there' always doubts. Read books, including those of a friend who passed away. Considered options with wife. Quality of life, cancer spread, difficulty of daily radiation in the winter, friend who had radiation and still not up to snuff. Threat to sex is big, even bigger for younger men and wives. Whatever you do, it'll cost you. Never know for sure if doing the right thing. That's why the doctor leaves it up to you, because you're the one that's got to live with it. |
| 29 | 2-4578: age 70, RP Decision Confidence: Moderate<br>Afraid of surgery; intimidated by local doctor; chose Richie; canceled surgery after attending Man-to-Man; read much; alternatives no good; *resigned* to surgery after all |
| 56 | 2-6349: age 58, RP Decision Confidence: Low<br>GP recommended seeds, easy, be done; then collected expert opinions; taken under wing by *Doctor* at *Hospital*; urologist and radiation doctor both recommended surgery; in the end, not rational, but wishful: close your eyes, trust, hope for the best, and take a dive. So taking their advice, mulling it over, wife and I *decided on primitive basis* for surgery; get it out of your body. So I was scheduled in July with great trepidation |
| **Resignation/Submission.** | |
| 36 | 1239620: age 72, RP Decision Confidence: Moderate<br>Precipitous surrender. Rather than feel sorry for myself, I told them to take it out; no talk of saving erections, wasn't getting any sex anyway |
| 30 | 1348470: age 57, EBRT Decision Confidence: Moderate<br>Resolved for surgery but really wasn't eager for the knife; radiation might leave sexual potency, but might lose it; surgery definitely lose it<br>Resignation: no good options, bodily losses, but I can deal with it; I'm still living |
| 34 | 1238660: age 69, RP Decision Confidence: Moderate<br>Realized I could not fool around with this [had to face up to this?], so did what I could to get it over with; resigned to surgery, preserving [what's left of] manhood, given depression. What are you going to do? It's the latest insult to self esteem. |
| 52 | 1100550: age 69, EBRT Decision Confidence: Low<br>Told could do nothing or do something; could outlive it; radiation might help; didn't want to end up in diapers<br>Tone of resignation: prospect of mortality, perhaps not, along with already lost potency due to high blood pressure |
| **Options were Limited.** | |
| 53 | 2-4065: age 75, EBRT Decision Confidence: Low<br>Did my research. Really wanted seeds; some friends got seeds on west coast, absolutely pleased; but MRI said I wouldn't benefit from seeds; wasn't for surgery at all; other friends had radiation; one friend had surgery, in terrible shape for a year, in a diaper; didn't want that |
| | |
| 28 | 2-6308: age 77; EBRT Decision Confidence: Moderate<br>Got second opinion with help of daughter; *options limited* by age and prior TURP to EBRT |
| 45 | 2-4102: age 78, EBRT Decision Confidence: Moderate<br>Not a slow cancer; little time; one doctor found mets, another didn't, a third proved no mets; said I could have external radiation; cardiac disease ruled out surgery |

| | |
|---|---|
| **EBRT Works (well enough)** | |
| 21 | 2-4448: age 80, EBRT Decision Confidence: High<br>Doctor son guided me to Boston; he took charge and the doctors decided; prostate cancer doesn't kill you for quite a while anyway |
| 24 | 2-4510: age 76, EBRT Decision Confidence: High<br>Doctors were leading towards seeds; daughters/nurses directed me to second opinion; seeds had no record; in awe of doctors at Farber who leaned towards radiation |
| 8 | 1346260R: age 74, EBRT Decision Confidence: High<br>It went up to cancer. And that's when they told me I had an option of either getting an operation or I could go ahead on for radiation. |
| 13 | 1101960: age 66, Watch → EBRT Decision Confidence: High<br>Prudent watcher. If PSA went over ten, I'd act. It did. Still possibility of cure, but I didn't want to take a chance on side effects |
| **EBRT to avoid Effects of RP** | |
| 6 | 1239820: age 74, EBRT Decision Confidence: High<br>Radiation would avoid friend's urinary troubles, and an operation could always be done later; and sex life might be preserved<br>Happy I chose radiation because it worked out great. |
| 10 | 1347800R: age 69, EBRT Decision Confidence: High<br>Radiation bad, surgery worse; Took the radiation; the operation, they cut too much, you won't be put back right; you won't pee, just drip; and it leaves a mark |
| 15 | 2-4127: age 66, EBRT Decision Confidence: High<br>Children, who are doctors, led me to Boston doctors who recommended radiation; and they wouldn't dictate; left decision to me. radiation better than overstated claims of Hopkins surgeon—how can they be so sure before they start? |
| 20 | 2-4431: age 72, EBRT Decision Confidence: High<br>Pushy doctors oversold surgery and seeds; *Doctor* and *Doctor*, not pushy, explained everything, took their treatment, got side effects, but they were sorry |
| 31 | 1100020R: age 79, EBRT Decision Confidence: Moderate<br>Able to dodge the awful therapy by choosing to go along with what was indicated; happily that was not surgery and the risk of wearing a diaper<br>Suggestion of diagnosis connoting prospect of therapy with emasculating consequences. By going with what the doctor said, so reassuringly, was able to avoid the awful. Relieved that it was only *menos mal.* |
| 32 | 1100260R: age 71, EBRT Decision Confidence: Moderate<br>Avoidance of complete operation—good reason to do that, but not necessary; try the less invasive, less costly alternative. Doctors and I chose radiation: acceptable, avoided invasive surgery and its side effects, though I was *no longer sexually attractive*<br>Rationalization of choice of non-aggressive strategy |
| 33 | 1101080: age 71, EBRT Decision Confidence: Moderate<br>Really afraid of the incontinence; Did not want to *end up wearing a diaper* and erectile dysfunction no longer mattered at age 65<br>[End up? Coming to the end of one's life back in diapers? An ignominious end.] |
| 40 | 1347210R: age 74, EBRT Decision Confidence: Moderate<br>I started sweating, but go ahead, do what you got to do, but I don't want an operation, no way; I've been cut four times in my rectum; they found they had to give me radiation |
| 46 | 2-4410: age 80, EBRT Decision Confidence: Moderate<br>Didn't want to wait; surgery seemed too invasive; surgery pushed by macho blowhard, but surgery meant big chance of diapers; radiation doctor sympathetic; relieved when he said he could do something about it; biopsy indicated severe cancer suggesting need for surgery, but radiation would work |

| | |
|---|---|
| **Brachytherapy to avoid Effects of RP** | |
| 42 | 1101400: age 66, brachytherapy Decision Confidence: Moderate<br>Many doctors, many books, dead set against surgery: not that serious, cutting the urethra, impotence; internal was four hour and then home, walking the dog; yet, Korda's complaints about surgery made him a crybaby |
| 43 | 1101570R: age 67, Brachytherapy and EBRT Decision Confidence: Moderate<br>Self determined person. Followed self-determined Andy Grove's lead, who came up smelling like a rose; fought off aggressive urologists, their biases, and the risk of diapers; considerate radiation oncologist willing to go along with seeds |
| 16 | 2-4156: age 85, Brachytherapy Decision Confidence: High<br>Avoid awful incontinence, unconcerned with risk of impotence, afraid of spreading cancer; still don't know what can be done if the seeds ever fail? Uncertainty countered by authority of Zietman. |
| 23 | 2-4485: age 67, Brachytherapy Decision Confidence: High<br>Learned cancer wouldn't kill me so chose least invasive course: MRI seeds, convenient, less incontinence, less impotence. But can't just watch and wait; walk around with cancer and worry, and cancer grows and kills you. |
| **Brachytherapy least Drastic** | |
| 17 | 2-4208: age 74, Brachytherapy Decision Confidence: High<br>Wasn't urgent, but get it out of the way with least down time |
| 18 | 2-4219: age 60, Brachytherapy Decision Confidence: High<br>Big shock, but learned I had time, learned that gold standard is oversold, old fashioned, barbaric; found seeds and clinical trial of MRI; given uncertainty, why opt for the most drastic |
| 55 | 2-4459: age 69, Brachytherapy Decision Confidence: Low<br>Ambivalence. Small cancer; could have convinced myself I could handle it and done nothing, but wife wanted aggressive; seeds appeared to be the easy way out; the safe way out with minimal negative risk of side effects; but PSA bounces around since so don't know if controlled or not, over treated or not. |
| **Skeptical, Reject Active Treatment** | |
| 38 | 1239780: age 75, Watch Decision Confidence: Moderate<br>Was afraid of the operation, and *older* people [> 70] favor watchful waiting anyway; sex was too small to matter |
| | |
| 47 | 2-4517: age 85, Watch → Hormone Decision Confidence: Moderate<br>Several opinions, including DFCI; male doctors urged action, female doctor said wait, so I did, 5 years until doctor urged action: Lupron; surgery left people screwed up, radiation not so wonderful either; wife had died after two [futile] operations for spreading bladder cancer; cure is unlikely; have to live with the possibility of disaster |
| **Resistance** | |
| 49 | 1346380: age 78, Watch Decision Confidence: Low<br>Defensive stance, resistance to doctors: Offered radiation, strenuously, because it [PSA] had moved; I said no; don't want nothing that will make me sick |
| 48 | 1239220: age 84, hormone therapy Decision Confidence: Low |

**Looking Forward and Looking Back at Decisions with Outcomes:**
**Preliminary Analysis of Prospective Qualitative Data**

The prospective, qualitative data collected in accomplishing Task 3 provide a unique opportunity to examine how men construct their experiences with early prostate cancer in their own terms and over time. Men were interviewed by telephone during the first few weeks after learning of their diagnosis, when they indicated to us that they had reached a decision on treatment, but had not yet begun treatment. They were interviewed again 12 months later. The initial interviews invited them to describe how they were dealing with prostate cancer. They told of their responses to the diagnosis, their decision making, and their anticipations of the consequences of their decisions. The follow up interviews invited them to describe how things had turned out.

Analysis of these data is in progress. We provide below an initial summary, based on eight cases.

*How they viewed their prostate cancer*

The news that they had prostate cancer was unpleasant, but there was little, explicit indication of distress. Only one of these men characterized the diagnosis as "a shock" and another said it was "surprising." However, for the former, the shock dissipated as he learned more about the cancer and his treatment options. Indeed, the more he learned, the less he felt he needed to pursue active treatment. In contrast, most of these men viewed the diagnosis as an imperative to active treatment. Prostate cancer was seen as likely to grow, spread, and eventually cause serious problems and likely their deaths. How soon this would occur varied. One man felt considerable urgency, as he wondered how long his prostate cancer had been growing without notice. Two men noted their doctors' attempts to provide reassurance by saying that early prostate cancer was not likely to be lethal, that it was curable. One took this to heart as the basis for deciding on what he thought was the least invasive therapeutic approach: brachytherapy. The other discounted these claims, worrying about survival as he embraced radical prostatectomy in order to rid himself of the disease. One 77 year old man said he would probably be dead in five years regardless of prostate cancer. His primary fear was that the cancer might make his last years painful.

*Their choices of therapy*

Five of these eight men chose radical prostatectomy. Their reasoning was that surgery would get rid of the cancer. Excision of the prostate was seen as excision of the tumor and, hence, the elimination of the cancer problem. Whereas four apparently reached this decision deliberately, one rather passively accepted the recommendation of his urologist to pursue surgery. His account had notes of mild disbelief and detachment, as he described how his wife and son, both lawyers, participated actively in his consultations with the doctor. It was they who pushed the decision for surgery, while he viewed the choice as making an unpleasant problem go away. One man chose brachytherapy, noting that his cancer was not a serious enough threat to warrant "radical" and "invasive" surgery. One chose primary androgen deprivation therapy over external beam radiation in order avoid side effects that he could only vaguely describe.

One chose to watch and wait. He describes becoming convinced that his prostate cancer was not lethal and that active treatment carried substantial risks of urinary and sexual dysfunction. Notwithstanding the recommendations of his doctors, friends, and men he met in a Man-to-Man support group, he opted to watch. Twelve months later he reported that he was still "hanging in there to see what would happen." It is worth noting that two of the men who chose active treatment delayed the initiation of treatment for extended periods. The man who chose primary androgen deprivation did not start his injections until 10 months after diagnosis. The man who chose brachytherapy reported in his follow up interview that he had continued to research his options and had just decided to start treatment.

There was little dissatisfaction about treatment choices 12 months later. Two of the five who had chosen surgery expressed misgivings about their decisions as they dealt with the side effects of treatment. One said that information he gained after surgery suggested that brachytherapy may have been a better approach. This came with second thoughts about how completely he had explored his options at the outset. Another man remained convinced of the wisdom of surgical removal, but he was unhappy that he had gone along with the "old fashioned" surgical approach favored by his Boston urologist, instead of pursuing a more innovative, less invasive approach of robotic, laparoscopic prostatectomy offered by a doctor in the Midwest.

*Interactions with doctors in reaching decisions*

Several of these men mentioned, either briefly or extensively, problematic interactions with their doctors. One man who chose radical prostatectomy pointed out at the outset that he *agreed* with his doctor that total removal was the best course. He said that his surgeon had explained all of his treatment options, but he also noted that he was indeed a surgeon and thus prejudiced in favor of radical prostatectomy. His doubt did not motivate a search of second opinions by others who might recommend external radiation or brachytherapy. However, he did consult alternative surgeons to find one with the greatest experience and thus, he expected, the greatest likelihood of successful treatment without side effects. He found one and proceeded with surgery, albeit with a small note of uncertainty. Yet, twelve months later and confronted with sexual dysfunction, he reproached himself for having foolishly relied on a chosen group of "salesmen." None of the these eight sought second opinions that might lead to alternative recommendations for therapy. One did, however, consult a second doctor in order to confirm the diagnosis.

Only one of the eight offered a contrasting note of praise for his doctor who communicated well and listened to his concerns. However, a few reported signs of misinformation resulting from their consultations. The man who opted for primary androgen deprivation said that he understood that the injections would put his cancer in remission for five years, after which it would likely spring back. He nonetheless went along with this approach thinking he was unlikely to live more than five years anyway, when he would be 82. He also reported that the injections would dry up his testosterone, which would stop the flow of semen and thus prevent erections. Another who chose surgery said he ran the risk of disrupting the testosterone tubes than ran near the prostate. That disruption was "like nerve damage" in that it cannot be repaired. The result would be the elimination of his *reproductive* capacity, although his doctor told him that nine times out of ten there is no damage to those tubes.

*Anticipated Outcomes*

Most of these men who chose active treatment expected therapeutic control of their cancer. Only two reported uncertainty 12 months later. Uncertainty was expressed by one who had chosen surgery in order to get rid of his cancer. He had also rejected radiation in order to avoid its unmentioned "side effects" and because radiation would preclude backup surgery if needed. As it turned out, his PSA did not return to zero as expected after surgery. He underwent adjuvant radiation and androgen ablation. The second man expressed uncertainty by noting that he could only presume that his cancer was under control. Both of these men reported worse than expected urinary and sexual dysfunction.

None of the five men who chose and underwent radical prostatectomy expected significant urinary dysfunction beyond acute post-operative problems necessitating a catheter. One, however, said a year later than things had turned out "terribly" because he had undergone three surgeries to correct what he described as scarring in his urethra. Two men reported problems with incontinence: one mild and the other severe. The first practiced Kegel exercises on a daily basis and was often mindful of the risks of losing control. If he felt a sneeze coming on he would automatically tighten his muscles. This was an effective adaptation. It also indicated that risk of embarrassing accidents was a constant presence in his life. The second reported a much more problematic experience. [026]

The six men who pursued active treatment reported in their follow up interviews that sexual dysfunction was a very unpleasant surprise. All had indicated that the risk of sexual problems was a consideration in reaching treatment decisions, although they tended to understate its importance at the time. The clearest statement of the salience of this risk was made by the man who opted to watch and wait. He simply could not pursue treatment that would likely end his ability to perform sexually. Yet, statements of the importance of sexual capability were much clearer at the follow up.

One man was surprised when he learned that what he had mistakenly understood as a risk to his reproductive capacity was actually a risk to his erectile capacity. At baseline he was sanguine and wistful about the possible end of reproduction. At 12 months his feelings had changed.

Data Extract 40

Int: What did they tell you you could expect? I mean, thinking back a year or so ago, what did they tell you you were getting into?

PT: Well they told me that there would be no problems, because they caught the cancer in the prostate and it supposedly hadn't moved or gone to any other areas involved in there. But they told me, by removing the prostate-- Of course you're not going to have any reproduction anymore, but that was all I was going to lose. They said you would still be able to have sex and all that stuff, and you'll be fine. But it didn't turn out that way. It's been almost a year, and I still haven't had one erection yet.

Int: Well I have to ask, how do you feel about that?

PT: I'm disappointed. So's my woman, here.

Int: Mr. [Name], I think you're mincing words on me. I need to know candidly, man-to-man, I mean, how do you deal with this stuff?

PT: I don't like it. I wish I could talk to somebody, and they would tell me that this will go away. But right now, I have no idea if this is going to ever cease, or if it's going to be a thing I'm going to have to live with. I don't know, I have no idea.

Another man stated prior to treatment that he was willing to sacrifice some sexual function in order to be sure of curing the prostate cancer. However, at 12 months he was extremely distressed to learn that a small sacrifice was turning out to be a permanent and total loss.

Data Extract 41

PT: Well, a year ago, I thought I was going to come back. This was just a pain in the ass operation and a year from now I would be right back to normal. That isn't what happened. Now that I've talked to other people that have had this and they are all experiencing what I am and I'm the one with only one year behind me. And I know that it's not going to get any better. I'm not kidding myself anymore and I'm accepting it and going on from there. Or maybe I just assumed that everything was going to be better than what I ended up with. I thought I was listening pretty good to him prior to the operation and I thought that it was something like an appendix and you go in and everything comes back to normal. The appendix, you never knew what it did anyway. The prostate really does do something. It does control one big part of your life.
Int: Yeah. Are you blaming yourself for making a bad decision?
PT: No. I made the right decision. I have no doubt in my mind that I made the right decision. There were other options out there I didn't find out about it until after the-- And I would have liked to pursue them a little further. I have not pursued them. It's too late to do anything now

Two men expressed a reluctant stoicism in dealing with the worse than expected sexual function. One described the loss as a "big drawback" of surgery and lamented the problems of awkwardly managing sexual performance with Viagra (largely ineffective) and penile injections, which diminished the pleasurable spontaneity of sex.

Data Extract 42

That's the only drawback. I have to admit that. That is a big drawback. I don't know if some people like it. You do it, but it's not-- You really have to plan for it. You know, injection, wait. I'm kind of spontaneous. Spontaneity is out of it. It's got to be a planned-for thing. So, we probably have sex less often than we did before, but we still have sex. That part, at least I know I can still function, just not the way I would like to. At least for the time being. Whether that improves or not, we'll have to wait and see.

Data Extract 43

Int: Well, you lose spontaneity. How does the negotiation go now? Nobody's ever asked you that question, I'm sure.
PT: Usually if you get romantic and you want sex, there's always a signal. She can tell, you can tell. But it's different now. It's strange now. It's not like it was. I don't mean strange. If I say let's have sex, she'll say go inject. We joke about it. But there's not much, really, you can do. I mean there are times when we're cuddling or doing things like that and I'll say, okay, let's go, but you've got to give me ten minutes. And that's it. Sometimes, oh, I don't want to go through that needle crap. Forget about it. And, so, I just walk away from it. And I never walked away before. But sometimes it's a pain in the butt and I just don't want to do it. I don't want to do it, and that's something. But, for the most part, that part is not the same. I don't care what any man says. I don't care when he says it's great or this or that. It's not natural, let's put it that way. And I think, though, that what we've done is we've come to an arrangement, my wife and I, about when we want to do it, we'll do it. You can inject and get ready and all that stuff and then we just go. And then there's no problem. Then it's like normal. Once it's erect, there's no problem whatsoever. But it's the preparation and the goofing around sometimes.
Int: Yes. It sounds like the way you signal each other may be different now.
PT: Oh, yes. That's different. Well, we kind of kid about it. I don't know if it's good or bad. You've got to find a way. My wife says, well, I'm always here any time you want. But that, to me, even sounds worse. We're both accommodating, let's put it what way. If she wants it, I'll do it. If I want it, she'll do it. So, there's no problem.
Int: You say it sounds worse. She's taking away your initiative?
PT: No. I'm still the one who, believe it or not, I'm still the one who asks most of the time or takes the initiative most of the time. That hasn't changed. It's just that sometimes I may not do it. I'll tell

you, she doesn't complain, so I'm not worrying about it right now. But I would like to be normal. Whether it is or not, I can deal with it, but it's not something I wish on any man.

## KEY RESEARCH ACCOMPLISHMENTS

- We have evaluated men's perceptions of the central outcome of prostate cancer treatment – cancer control – and the quality of their treatment decisions long after reaching those decisions in a cohort of survivors.
- While perceived cancer control and feelings about one's treatment decisions are related, men who live with the outcomes of these decisions clearly distinguish between these two outcomes.
- Perceptions of cancer control are closely related to objective, clinical attributes of prostate cancer. It is diminished by:
    - pre-treatment prognostic signs indicating elevated risk of subsequent PSA failure
    - rising PSA after primary treatment
    - receipt of secondary androgen ablation
- Confidence in one's treatment decisions is related to perceived cancer control, but is unrelated to the correlates of perceived cancer control.
- Confidence in one's treatment decisions greater among those who:
    - received surgery or brachytherapy, instead of external radiation
    - pay close attention to PSA
    - are married
    - report masculine self esteem
    - report little distress with treatment-related sexual dysfunction
- We have developed a large, integrated, qualitative data base containing the open-ended, first person accounts of a diverse group of men who have survived between one and eight years since receiving a diagnosis of early prostate cancer, reaching a decision on therapy, and embarking on lives with prostate cancer. These data have provided—and will continue to provide—a rich basis for studies of decisions, outcomes, and understanding of prostate cancer as a chronic illness.
- We have defined five principal components of men's stories of their decisions and outcomes
    - Disease: qualities of the cancer
    - Disease acts: discovery, decision making, and treatment
    - Physical dysfunction following treatment:
        - urinary incontinence and control
        - bowel problems
        - sexual dysfunction
    - Social context:
        - interactions with doctors and others in medical settings
        - intimate partner relationships
        - family and friend relationships
    - Identity issues, that is how the diagnosis and the experience dealing with treatment and subsequent bodily changes affect and are affected by one's identity.

- Prostate cancer, as a central object constructed in men's stories, has a complex character, with multiple attributes that impinge on men's actions. These attributes vary. As they vary the constitute configurations of objective circumstances, that is, how men *make sense* of their cancer, that determine men's reasonable responses to the diagnosis. They include:
    - tendency to grow steadily and inexorably
    - controllability
    - visibility, primarily through PSA readings
    - personal relevance of the cancer
    - personality—agency—of the prostate cancer as more or less willful
    - lethality
    - a cause of personal diminishment and disintegration
- Doctors play complex roles in men's narratives of decisions and outcomes. They may be cast in the following roles and be described as performing well or poorly in these roles:
- discoverer of the cancer
    - informant of medical options
    - reference/referral link
    - guide to understanding medical information
    - ratifier of one's choices
    - supporter, providing emotional and instrumental support
    - provider of services
    - collaborator
- Urinary dysfunction has multiple effects on behavior, relationships, and identity. The construction of urinary dysfunction in men's accounts is built on five components
    - physical experiences of urination and controlling urination
    - practical problems in dealing with impaired urinary control
    - etiology of urinary problems
    - communication about urinary problems
    - effects of urinary problems on emotional well-being and self-image
- Sexual dysfunction is far more complex than bothersome erectile dysfunction; it has ramifications in multiple domains.
    - bodily function
    - drive, interest, libido
    - performance and intimate behavior
    - use of assistance and assistive devices in support of performance
    - relational nature of sexuality
    - issues of disclosure
    - sexuality as vitality
    - masculinity
- We defined 11 profiles of decision making in men's accounts
    - I followed the doctor
    - I followed the doctor, with some diffidence
    - I sought to cure the cancer
    - I went forward, with trepidation
    - I went forward, with resignation

- Options were limited
- External radiation is not removal, but works well enough and avoids the unpleasant side effects of surgery
- External radiation simply avoids the unpleasant side effects of surgery
- Brachytherapy avoids the side effects of surgery
- Brachytherapy was the least drastic approach to dealing with prostate cancer
- Skeptical and resistant to active therapy

- The profiles of decision making provide the basis for innovative, patient-centered approaches to facilitating informed decision making—one that takes account of the complex roles and cognitive orientations that men adopt in response to the challenge posed by the diagnosis and imperative of deciding an approach to treatment.

**REPORTABLE OUTCOMES**

Interim findings provide verification of psychosocial dimensions of prostate cancer-related quality of life, as reported in recently published findings from our previous research.[1] Preliminary analyses of interviews suggest that we will be able to explore and explicate life changes, suggested in recent analyses of cross-sectional survey data, through planned analyses of men's narratives.[2]

The research team has been expanded by the addition of Dr. Lorrie Powel. Her study of quality of life outcomes associated with post-prostatectomy urinary incontinence has been supported by DoD as a post-doctoral training grant, under the supervision of Dr. Jack A. Clark (DAMD17-02-1-0236). Dr. Powel brings extensive clinical experience in nursing to the project. While Dr. Powel's project is a separate undertaking, her training will include participation in the analysis of data collected in the present study. In addition, Dr. Barbara G. Bokhour, co-investigator, has recently completed the first year of a two-year study, funded by the National Cancer Institute (RO3 CA 91737001), to explore the clinical utility of the qualitative findings derived from the present study. As a result, the overall project has been strengthened by clinical expertise and an direct examination of the clinical utility of the findings, as they emerge.

Findings of this study are being used to inform the development of a patient decision making support intervention, in collaboration with investigators at and supported by a pilot study grant from the Massachusetts General Hospital. It is being built on the well-tested template of Consultation Planning and Consultation Recording (CP/CR) programs designed to facilitate patient participation in treatment decision making.[9,10,11] The CP/CR approach was originally developed for women with breast cancer and their doctors. Materials for this study of decisions and outcomes in prostate cancer are providing the substantive basis for the adaptation of CP/CR to this setting.

Presentations:

Bokhour, BG and JA Clark. *Quality of Life and Sexuality after Prostate Cancer.* The Fifth Annual Massachusetts Prostate Cancer Symposium, May 2002. Marlborough, MA

Bokhour, BG *No less a man: Men's stories of surviving prostate cancer.* American Association of Applied Linguistics Annual Conference, March 2003. Arlington, VA.

Bokhour, BG *"Part of me is not what it used to be": Reconstructing identity in early prostate cancer.* Eighth Annual Language and Social Interaction in Communication Round Table, October 2001, West Greenwich, Rhode Island

Bokhour, BG and JA Clark. *Men's stories of surviving prostate cancer.* Cancer Survivorship: Resilience Across the Lifespan. National Cancer Institutes and American Cancer Society. June 2002, Washington, DC

Bokhour, BG. *Prostate cancer survivor narratives and doctors' responses.* Small grants program for behavioral research in cancer control, National Cancer Institute, December 2002. Bethesda, MD

Clark J, Talcott J. Decisions and Cancer Control: Perceptions of Prostate Cancer Survivors. Presentation at the Annual Meeting of the Department of Veterans Affairs Health Services Research and Development Service, Washington, DC, March 2004.

Manuscripts in Preparation:

Bokhour B, Powel L, Clark J. No less a man: reconstructing identity after prostate cancer. to be submitted as part of a special issue of *Communication & Medicine: Constructing Identity in Medical Discourses*

Bokhour B, Clark J. Caring for survivors of prostate cancer: The practice of primary care physicians and urologists. to be submitted to *Journal of General Internal Medicine.*

Clark J, Talcott J. Living with uncertainty after treatment for early prostate cancer: survivors' views of cancer control and the treatment decisions they made. under review by *Medical Decision Making*

Clark J, Bokhour B, Talcott J. Prostate cancer treatment decisions: patients' views looking forward and looking back. to be submitted *Cancer*

Clark J, Bokhour B, Talcott J. Looking back at what had to be done: men's accounts of treatment decisions in early prostate cancer. to be submitted to *Medical Care*

Clark J, Bokhour B, Powel L, Talcott J. Qualities of sexuality after treatment for early prostate cancer. to be submitted to *Social Science and Medicine*

Powel L, Clark J, Bokhour B, Talcott J. Qualities of urinary dysfunction after treatment for early prostate cancer. to be submitted to *Social Science and Medicine*

## CONCLUSIONS

Subject accrual was accomplished as expected at the Buffalo site in completing Task 3. However, subject accrual was not successfully initiated at the Washington DC site because of substantial delays in the granting of final approval by the local IRB. The IRB was audited by the VA in the Fall and Winter of 2001/2002, resulting in significant delays in the processing of protocols. While we had anticipated that this problem would be resolved, our expectations were not met. We explored and secured the participation of an additional site in order to meet subject accrual goals: the urology clinic at Boston Medical Center. The investigators have a relationship with this clinic, developed in previous studies. The clinic also serves a racially and economically diverse population, thus it would be suitable to the goals of the study, including analyses of quality of life changes associated with treatment for early prostate cancer in a diverse population.

The results of this study will be useful in several ways. They will guide the design of future, large scale studies of the processes and outcomes of care for early prostate cancer. Yet, they will have more immediate utility. They will provide informative materials for health care providers about the significant changes men see themselves as undergoing. They will also provide information to men who face the ominous diagnosis and those who continue to live with the outcomes of their treatment. Moreover, we will provide information about the changes men experience in the understandable form of men's stories.

## REFERENCES


1. Talcott J, Manola J, Clark J, Kaplan I, Beard C, Mitchell S, Chen R, O'Leary M, Kantoff P, D'Amico A. Time course and predictors of symptoms after primary prostate cancer therapy. *Journal of Clinical Oncology* 2003;21:3979-3986.
2. Talcott J, Clark J. Quality of life in prostate cancer. *European Journal of Cancer* 2005;41:922-931.
3. Clark J, Bokhour B, Inui T, Silliman R, Talcott J. Measuring patients' perceptions of the outcomes of treatment for early prostate cancer. *Medical Care*, 2003;41:923-936.
4. Clark J, Inui T, Silliman R, Bokhour B, Krasnow S, Robinson R, Spaulding M, Talcott J. Patients' perceptions of quality of life after treatment for early prostate cancer. *Journal of Clinical Oncology*, 2003;21:3777-3784.
5. Litwin M, Hays R, Fink A, Ganz P, Leake B, Brook R. The UCLA Prostate Cancer Index: development, reliability, and validity of a health-related quality of life measure. *Medical Care* 1998;36:1002-1012.
6. Wei J, Dunn R, Litwin M, Sandler H, Sanda M. Development and validation of the expanded prostate cancer index composite (EPIC) for comprehensive assessment of health-related quality of life in men with prostate cancer. *Urology* 2000;56:899-905.
7. Clark J, Talcott J. Symptom indexes to assess outcomes of treatment for early prostate cancer. *Medical Care* 2001;39:1118-1130.
8. Bokhour J, Clark J, Inui T, Silliman R, Talcott J. Sexuality after treatment for early prostate cancer: exploring the meanings of "erectile dysfunction." *Journal of General Internal Medicine*, 2001; 16:649-655.

9. Sepucha KR, Belkora JK, Mutchnick S, Esserman LJ. Consultation planning to help breast cancer patients prepare for medical consultations: effect on communication and satisfaction for patients and physicians. *Journal of Clinical Oncology* 2002;20:2695-700.
10. Sepucha KR, Belkora JK, Tripathy D, Esserman LJ. Building bridges between physicians and patients: results of a pilot study examining new tools for collaborative decision making in breast cancer. *Journal of Clinical Oncology* 2000;18:1230-8.
11 Sepucha KR, Belkora JK, Aviv C, Mutchnik S, Esserman LJ. Improving the quality of decision making in breast cancer: consultation planning template and consultation recording template. *Oncology Nursing Forum* 2003;30:99-106.

## APPENDICES

Survey Questionnaire Used in Accomplishing Task 2

## Section One: Treatment for Your Prostate Cancer

**The questions in this section ask about the treatment you have received for prostate cancer. First, we ask about treatment during the first 6 months after getting the diagnosis. Since your situation may have changed, we will then ask about your treatment in the years after the first 6 months following your diagnosis.**

1. What treatments did you receive **during the first 6 months** after your prostate cancer was diagnosed?
Please answer every question, 1a through 1h below, since every man's case is unique and sometimes more than one treatment appears necessary.

| | | Yes | No |
|---|---|---|---|
| a. | Did you decide not to do anything for the time being (watch and wait)? | 1 | 2 |
| b. | Did you have an operation to remove your prostate (a radical prostatectomy)? | 1 | 2 |
| c. | Did you have a procedure in which radioactive seeds were implanted in your prostate (brachytherapy)? | 1 | 2 |
| d. | Did you receive a course of daily radiation treatment (external beam radiation)? This may be done by itself or added after surgery or radioactive seeds (brachytherapy). | 1 | 2 |
| e. | Did you have a procedure in which your prostate was frozen (cryotherapy)? | 1 | 2 |
| f. | Did you receive a *brief course (less than 1 year)* of hormone treatment (injections, pills or both) around the time you were diagnosed, or along with another treatment, such as surgery, radiation or seeds? | 1 | 2 |
| g. | Did you start a long-term course of hormone treatment (injections, pills or both) for more than 12 months or that you continue to receive? | 1 | 2 |
| h. | Did you have an operation in which your testicles were removed (an orchiectomy)? | 1 | 2 |

2. **During the first 6 months**, how many doctors did you talk to about how your prostate cancer should be treated?

**Write in number of doctors**

3. **During the first 6 months**, did any doctor you talked to offer you a choice between two or more types of treatment for your prostate cancer?

| Yes | No |
|---|---|
| 1 | 2 |

4. **During the first 6 months**, did you get different recommendations about the best treatment from different doctors you talked to?

| Yes, I got different recommendations | No, all doctors recommended the same treatment | I talked to only one doctor |
|---|---|---|
| 1 | 2 | 3 |

5. Each man and his doctor may reach the decision on which treatment a man should get for early prostate cancer in a different way. Which statement best describes how the treatment you received **during the first 6 months** was chosen?

| The choice was mostly my doctor's; my doctor made the decision or made a strong recommendation | My doctor and I came to the decision together | The choice was mostly mine; my doctor left the decision entirely or mostly up to me |
|---|---|---|
| 1 | 2 | 3 |

**Treatment for your prostate cancer since the first 6 months.**

6. After your first treatment for prostate cancer, did your PSA ever start to go up again?

Yes **1** No **2** Don't Know **3**

7. The last time you heard from your doctor, what was your PSA doing?

Falling **1** Staying the same **2** Rising **3** Don't Know **4**

8. What was your **most recent** PSA result? ☐

**Write in the approximate number**

Don't know; check here ☐

**Treatment for your prostate cancer since the first 6 months.**

9. In the years following the first 6 months after diagnosis, what treatments have you received?
Since every man's case is unique and more than one treatment may be necessary at different times, be sure to mark an answer for each of these questions, 8a through 8h.

| | | Yes | No |
|---|---|---|---|
| a. | Did you decide not to do anything for the time being (continue to watch and wait)? | 1 | 2 |
| b. | Did you have an operation to remove your prostate (a radical prostatectomy)? | 1 | 2 |
| c. | Did you have a procedure in which radioactive seeds were implanted in your prostate (brachytherapy)? | 1 | 2 |
| d. | Did you receive a course of daily radiation treatment (external beam radiation)? This may be done by itself or added after surgery or radioactive seeds (brachytherapy). | 1 | 2 |
| e. | Did you have a procedure in which your prostate was frozen (cryotherapy)? | 1 | 2 |
| f. | Did you receive a *brief course (less than 1 year)* of hormone treatment (injections, pills or both) around the time you were diagnosed, or along with another treatment, such as surgery, radiation or seeds? | 1 | 2 |
| g. | Did you start a long-term course of hormone treatment (injections or pills) for more than 12 months or that you continue to receive? | 1 | 2 |
| h. | Did you have an operation in which your testicles were removed (an orchiectomy)? | 1 | 2 |

## Section Two: Urinary Problems

1. **In the past week**, how easy has your urine flow been?

| Very easy | Fairly easy | Slow, but I don't have to strain or bear down | Slow, and I do have to strain or bear down | Very slow, and I have to strain or bear down hard |
|---|---|---|---|---|
| **1** | **2** | **3** | **4** | **5** |

2. **In the past week**, how often did you urinate at night?

| Seldom or never | Once a night | 2 to 3 times a night | More than three times a night |
|---|---|---|---|
| **1** | **2** | **3** | **4** |

3. **In the past week**, how often did you urinate?

| 4 or fewer times a day | 5 to 8 times a day | 9 to 12 times a day | More than 12 times a day |
|---|---|---|---|
| **1** | **2** | **3** | **4** |

4. **In the past week**, how often have you felt pain or burning during urination?

| Not at all | Occasionally | Fairly frequently | Frequently | Very frequently |
|---|---|---|---|---|
| **1** | **2** | **3** | **4** | **5** |

5. **In the past week**, how often have you urinated blood?

| Not at all | Occasionally | Fairly frequently | Frequently | Very frequently |
|---|---|---|---|---|
| **1** | **2** | **3** | **4** | **5** |

6. **In the past week,** how often did you have the feeling that it is urgent that you pass your urine?

| Not at all | Occasionally | Fairly frequently | Frequently | Very frequently |
|---|---|---|---|---|
| **1** | **2** | **3** | **4** | **5** |

7. **In the past week,** how much control did you have over your urine?

| Had complete control (no leaking) | Leaked urine, but only at certain times | Leaked urine most of the time | Little or no control |
|---|---|---|---|
| **1** | **2** | **3** | **4** |

8. **In the past week,** how often did you leak urine?

| Not at all | Occasionally | Fairly frequently | Frequently | Very frequently |
|---|---|---|---|---|
| **1** | **2** | **3** | **4** | **5** |

9. **IF YOU LEAKED URINE IN THE PAST WEEK,** how much usually comes out?

| Had complete control (no leaking) | A few drops | Less than a tablespoon | More than a tablespoon | Can't tell how much |
|---|---|---|---|---|
| **1** | **2** | **3** | **4** | **5** |

10. **In the past week,** did you wear a pad to absorb urine in your underwear?

| Yes | No |
|---|---|
| **1** | **2** |

10a. **In the past week,** if you wore a pad in your underwear, how often during the day did you change it?

| Not at all | Once or twice a day | Three or more times a day | Did not wear a pad |
|---|---|---|---|
| **1** | **2** | **3** | **4** |

11. How big a problem, if any, has each of the following been for you **during the past 4 weeks**?

| | **No Problem** | **Very Small Problem** | **Small Problem** | **Moderate Problem** | **Big Problem** |
|---|---|---|---|---|---|
| a. Dripping or leaking urine | **1** | **2** | **3** | **4** | **5** |
| b. Pain or burning on urination | **1** | **2** | **3** | **4** | **5** |
| c. Bleeding with urination | **1** | **2** | **3** | **4** | **5** |
| d. Weak urine stream or incomplete emptying | **1** | **2** | **3** | **4** | **5** |
| e. Waking up to urinate | **1** | **2** | **3** | **4** | **5** |
| f. Need to urinate frequently during the day | **1** | **2** | **3** | **4** | **5** |

12. **Overall**, how big a problem has your urinary function been for you **during the past 4 weeks**?

| No problem | Very small problem | Small problem | Moderate problem | Big problem |
|---|---|---|---|---|
| **1** | **2** | **3** | **4** | **5** |

Questions 13a – 13q ask about how you may feel about **urinary problems** and how they may affect your life. If you have no problems at all in these areas, simply circle the number under "not at all."

13. How true has each of the following statements been for you **during the past 4 weeks**?

| | | Not at All | A Little Bit | Somewhat | Quite a Bit | Very Much |
|---|---|---|---|---|---|---|
| a. | I worry about wetting myself. | 1 | 2 | 3 | 4 | 5 |
| b. | I worry about coughing or sneezing making me lose control. | 1 | 2 | 3 | 4 | 5 |
| c. | I worry about others smelling urine on me. | 1 | 2 | 3 | 4 | 5 |
| d. | I am careful to watch for any signal that I need to urinate. | 1 | 2 | 3 | 4 | 5 |
| e. | I am careful not to laugh, for fear of losing control. | 1 | 2 | 3 | 4 | 5 |
| f. | Leaking urine makes me feel dirty. | 1 | 2 | 3 | 4 | 5 |
| g. | I am sometimes embarrassed or humiliated because of my urinary problems. | 1 | 2 | 3 | 4 | 5 |
| h. | I'm often afraid of having an accident and making a mess. | 1 | 2 | 3 | 4 | 5 |
| i. | My urinary problems make me feel helpless. | 1 | 2 | 3 | 4 | 5 |
| j. | I feel nervous when I don't know where the bathrooms are. | 1 | 2 | 3 | 4 | 5 |
| k. | The need to urinate is never far from my mind. | 1 | 2 | 3 | 4 | 5 |
| l. | I can rely on my body to warn me that I need to urinate soon enough. | 1 | 2 | 3 | 4 | 5 |
| m. | My urinary problems complicate everything I do. | 1 | 2 | 3 | 4 | 5 |
| n. | The things I have to do to just to urinate are embarrassing. | 1 | 2 | 3 | 4 | 5 |
| o. | I avoid situations in which I might not be able to get to a bathroom in time. | 1 | 2 | 3 | 4 | 5 |
| p. | My urinary problems have affected my enjoyment of life. | 1 | 2 | 3 | 4 | 5 |
| q. | Urination makes me miserable. | 1 | 2 | 3 | 4 | 5 |

## Section Three: Bowel Problems

**The questions in this section ask about bowel problems that may be caused by various physical conditions.**

1. **In the past week,** how often did you have diarrhea, or loose, watery stools?

| Not at all | Occasionally | Fairly frequently | Frequently | Very frequently |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

2. **In the past week,** how often did you have a sense of urgency that you move your bowels?

| Not at all | Occasionally | Fairly frequently | Frequently | Very frequently |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

3. **In the past week,** how often did you have tenderness or pain when you move your bowels?

| Not at all | Occasionally | Fairly frequently | Frequently | Very frequently |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

4. **In the past week,** how often did you have bleeding with your bowel movements?

| Not at all | Occasionally | Fairly frequently | Frequently | Very frequently |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

5. **In the past week,** how often did you have abdominal cramping or pain?

| Not at all | Occasionally | Fairly frequently | Frequently | Very frequently |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

6. **In the past week,** how often have you passed mucus from your rectum?

| Not at all | Occasionally | Fairly frequently | Frequently | Very frequently |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

7. **In the past week,** how often did you have the feeling that you have an urge to move your bowels, but have nothing to pass?

| Not at all | Occasionally | Fairly frequently | Frequently | Very frequently |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

8. How big a problem, if any, has each of the following been for you **during the past 4 weeks**?

| | | **No Problem** | **Very Small Problem** | **Small Problem** | **Moderate Problem** | **Big Problem** |
|---|---|---|---|---|---|---|
| a. | Urgency to have a bowel movement | 1 | 2 | 3 | 4 | 5 |
| b. | Increased frequency of bowel movements | 1 | 2 | 3 | 4 | 5 |
| c. | Watery bowel movements | 1 | 2 | 3 | 4 | 5 |
| d. | Losing control of your stools | 1 | 2 | 3 | 4 | 5 |
| e. | Bloody stools | 1 | 2 | 3 | 4 | 5 |
| f. | Abdominal/pelvic/rectal pain | 1 | 2 | 3 | 4 | 5 |

9. **Overall**, how big a problem have your bowel habits been for you **during the past 4 weeks**?

| No problem | Very small problem | Small problem | Moderate problem | Big problem |
|---|---|---|---|---|
| **1** | **2** | **3** | **4** | **5** |

Questions 10a – 10h ask about how you may feel about **bowel problems** and how they may affect your life. If you have no problems at all in these areas, simply circle the number under "not at all."

13. How true has each of the following statements been for you **during the past 4 weeks**?

| | | NOT AT ALL | A LITTLE BIT | SOMEWHAT | QUITE A BIT | VERY MUCH |
|---|---|---|---|---|---|---|
| a. | I worry about soiling myself. | 1 | 2 | 3 | 4 | 5 |
| b. | I am careful to watch for any signal that I need to have a bowel movement. | 1 | 2 | 3 | 4 | 5 |
| c. | My bowel problems make me feel helpless. | 1 | 2 | 3 | 4 | 5 |
| d. | I feel nervous when I don't know where the bathrooms are. | 1 | 2 | 3 | 4 | 5 |
| e. | The need to move my bowels is never far from my mind. | 1 | 2 | 3 | 4 | 5 |
| f. | I can rely on my body to warn me that I need to have a bowel movement soon enough. | 1 | 2 | 3 | 4 | 5 |
| g. | My bowel problems complicate everything I do. | 1 | 2 | 3 | 4 | 5 |
| h. | My bowel problems have affected my enjoyment of life. | 1 | 2 | 3 | 4 | 5 |

## Section Four: Sexual Functioning

1. **In the past 4 weeks,** how interested in sex have you been?

| Not at all | Slightly | Moderately | Quite a bit | Extremely |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

2. **In the past 4 weeks,** how often have you felt sexual desire?

| Almost never/never | A few times (less than half the time) | Sometimes (about half the time) | Most times (more than half the time) | Almost always/always |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

3. In the past 4 weeks, how would you rate your level of sexual desire?

| Very low/none at all | Low | Moderate | High | Very high |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

4. **In the past 4 weeks,** have you had any erections at all (including morning erections)?

| Yes | Yes, morning erections only | No |
|---|---|---|
| **1** | **2** | **3** |

5. **In the past 4 weeks,** what is the most erect (or hard) your penis has become at any time?

| Full erection | Nearly full erection - sufficient for penetration without manual assistance | Partial erection - capable of penetration with manual assistance | Partial erection - not capable of penetration even with manual assistance **4** | No erection at all |
|---|---|---|---|---|
| **1** | **2** | **3** | | **5** |

6. **In the past 4 weeks,** what is the most erect (or hard) your penis has become at any time without the use of Viagra, Erec-Aid or any other type of erection aid?

| Full erection | Nearly full erection - sufficient for penetration without manual assistance | Partial erection - capable of penetration with manual assistance | Partial erection - not capable of penetration even with manual assistance | No erection at all |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

7. **In the past 4 weeks,** how much difficulty have you had getting an erection during sexual activity?

| A lot | Some | A little | No difficulty | Have not had sexual activity |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

8. **In the past 4 weeks,** how much difficulty have you had keeping an erection during sexual activity?

| A lot | Some | A little | No difficulty | Have not had sexual activity |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

9. **In the past 4 weeks,** have you been able to reach orgasm (sensation of climax)?

| Yes, all the time | Yes, some of the time | No, not at all | Have not engaged in sexual activity in the past 4 weeks |
|---|---|---|---|
| 1 | 2 | 3 | 4 |

10. **In the past 4 weeks,** have you been able to ejaculate?

| Yes, all the time | Yes, some of the time | No, not at all | Have not engaged in sexual activity in the past 4 weeks |
|---|---|---|---|
| 1 | 2 | 3 | 4 |

11. **In the past 4 weeks,** how satisfied have you been with your sex life?

| Extremely satisfied | Somewhat satisfied | Neither satisfied nor dissatisfied | Somewhat dissatisfied | Extremely dissatisfied |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

12. **In the past 4 weeks,** how much have you cared about having an active sex life?

| Not at all | A little | Some | A lot |
|---|---|---|---|
| 1 | 2 | 3 | 4 |

13. How big a problem, if any, has each of the following been for you during **the past four weeks**?

| | | No Problem | Very Small Problem | Small Problem | Moderate Problem | Big Problem |
|---|---|---|---|---|---|---|
| a. | Your level of sexual desire | 1 | 2 | 3 | 4 | 5 |
| b. | Your ability to relax an enjoy sex | 1 | 2 | 3 | 4 | 5 |
| c. | Your ability to become sexually aroused | 1 | 2 | 3 | 4 | 5 |
| d. | Your ability to have an erection | 1 | 2 | 3 | 4 | 5 |
| e. | Your ability to reach orgasm | 1 | 2 | 3 | 4 | 5 |

13. **Overall**, how big a problem has your sexual function or lack of sexual function been for you during **the past 4 weeks**?

| No problem | Very small problem | Small problem | Moderate problem | Big problem |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

14. How true has each of the following statements been for you **during the past 4 weeks**?

| | | Not at All | A Little Bit | Somewhat | Quite a Bit | Very Much |
|---|---|---|---|---|---|---|
| b. | I'm confident in my sexual ability. | 1 | 2 | 3 | 4 | 5 |
| c. | Trying to have sex is too complicated. | 1 | 2 | 3 | 4 | 5 |
| d. | My sex life feels unnatural to me. | 1 | 2 | 3 | 4 | 5 |
| e. | I am able to enjoy physical intimacy. | 1 | 2 | 3 | 4 | 5 |
| f. | I feel helpless to act on my sexual urges. | 1 | 2 | 3 | 4 | 5 |
| g. | When it comes to getting close physically, I have to be careful not to start something I can't finish. | 1 | 2 | 3 | 4 | 5 |
| h. | I am worried that I might embarrass myself if I try to have sex. | 1 | 2 | 3 | 4 | 5 |
| i. | I feel good about my sexuality. | 1 | 2 | 3 | 4 | 5 |
| j. | Thinking about my sex life leaves me with an uneasy feeling. | 1 | 2 | 3 | 4 | 5 |
| k. | When I hear talk about sex I feel like the odd man out. | 1 | 2 | 3 | 4 | 5 |
| l. | I feel good about the way I deal with my own sexual needs and desires. | 1 | 2 | 3 | 4 | 5 |
| m. | It feels good to think about sex. | 1 | 2 | 3 | 4 | 5 |
| n. | I would feel ill at ease if someone flirted with me. | 1 | 2 | 3 | 4 | 5 |

**New treatments have become available for problems with sexual function. Questions 15a—15f ask about your experience with these treatments.**

15. Which statement best describes your experience with each of these sexual function treatments **in the past 12 months**?

| | | Have not used this in the past 12 months | Have used this and plan to use it again | Have used this, but do not plan to use it again |
|---|---|---|---|---|
| a. | Viagra | 1 | 2 | 3 |
| b | Yohimbe | 1 | 2 | 3 |
| c. | Medicine inserted into the tip of the penis (MUSE) | 1 | 2 | 3 |
| d. | Erec-Aid or other vacuum device | 1 | 2 | 3 |
| e. | Injection therapy (medicine injected into a vein in the penis) | 1 | 2 | 3 |
| f. | Penile prosthesis | 1 | 2 | 3 |

## Section Five: Social Relationships

1. How true has each of the following statements been for you **during the past 4 weeks**?

| | | Not at All | A Little Bit | Somewhat | Quite a Bit | Very Much |
|---|---|---|---|---|---|---|
| a. | I avoid other people. | 1 | 2 | 3 | 4 | 5 |
| b. | I feel that other people are avoiding me. | 1 | 2 | 3 | 4 | 5 |
| c. | I feel odd and different from other people. | 1 | 2 | 3 | 4 | 5 |
| d. | I feel self-conscious and embarrassed. | 1 | 2 | 3 | 4 | 5 |
| e. | I am able to take care of the people who depend on me. | 1 | 2 | 3 | 4 | 5 |

2. About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)?
Write in the number of close friends and relatives

3. People sometimes look to others for companionship, assistance or other types of support. How often is each of the following kinds of support available to you if you need it?

| | | None of the Time | A Little of the Time | Some of the Time | Most of the Time | All of the Time |
|---|---|---|---|---|---|---|
| a. | Someone to confide in or talk to about yourself or your problems. | 1 | 2 | 3 | 4 | 5 |
| b. | Someone to get together with for relaxation. | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|---|---|---|---|---|---|---|
| c. | Someone to help with daily chores if you were sick. | 1 | 2 | 3 | 4 | 5 |
| d. | Someone to turn to for suggestions about how to deal with a personal problem. | 1 | 2 | 3 | 4 | 5 |
| e. | Someone to love and make you feel wanted. | 1 | 2 | 3 | 4 | 5 |

The following statements are about your relationship with **your spouse or partner**.

4. Do you have a spouse or a partner who is like a spouse to you?

| Yes | No |
|---|---|
| **1** | **2** |

→ If **NO**, go to **Section Seven**.

5. **In the past 4 weeks**, how TRUE or FALSE has each of the following statements been for you and your spouse or partner?

| | | **Definitely True** | **Mostly True** | **Don't Know** | **Mostly False** | **Definitely False** |
|---|---|---|---|---|---|---|
| a. | We said anything we wanted to say to each other. | **1** | **2** | **3** | **4** | **5** |
| b. | We often had trouble sharing our personal feelings. | **1** | **2** | **3** | **4** | **5** |
| c. | It was hard to blow off steam with each other. | **1** | **2** | **3** | **4** | **5** |
| d. | I felt close to my spouse or partner. | **1** | **2** | **3** | **4** | **5** |
| e. | My spouse or partner was supportive of me. | **1** | **2** | **3** | **4** | **5** |
| f. | We tended to rely on other people for help rather than on each other. | **1** | **2** | **3** | **4** | **5** |
| g. | My spouse or partner is satisfied with our sex life. | **1** | **2** | **3** | **4** | **5** |

6. How true has each of the following statements been for you **during the past 4 weeks**?

| | | NOT AT ALL | A LITTLE BIT | SOMEWHAT | QUITE A BIT | VERY MUCH |
|---|---|---|---|---|---|---|
| a. | I feel uncomfortable when my spouse or partner acts very affectionate. | 1 | 2 | 3 | 4 | 5 |
| b. | My spouse or partner seems cool and distant from me. | 1 | 2 | 3 | 4 | 5 |
| c. | My partner avoids embracing, kissing or caressing me. | 1 | 2 | 3 | 4 | 5 |
| e. | I feel that my spouse or partner may want to turn to others for affection. | 1 | 2 | 3 | 4 | 5 |
| g. | I do a good job taking care of my spouse or partner. | 1 | 2 | 3 | 4 | 5 |
| h. | My spouse or partner understands completely what I've gone through with prostate cancer. | 1 | 2 | 3 | 4 | 5 |

7. How would you rate your spouse's health in general?

| Excellent | Very Good | Good | Fair | Poor |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

## Section Six: How You Feel About Yourself

1. How true has each of the following statements been for you **during the past 4 weeks**?

| | | Not at All | A Little Bit | Somewhat | Quite a Bit | Very Much |
|---|---|---|---|---|---|---|
| a. | I have negative feelings about the way my body looks. | 1 | 2 | 3 | 4 | 5 |
| b. | I avoid being seen without a shirt on. | 1 | 2 | 3 | 4 | 5 |
| c. | I have been concerned about loss of muscle tone. | 1 | 2 | 3 | 4 | 5 |
| d. | I feel that my body is getting soft and flabby. | 1 | 2 | 3 | 4 | 5 |
| e. | I worry about becoming dependent on others. | 1 | 2 | 3 | 4 | 5 |
| f. | I am embarrassed about my physical condition. | 1 | 2 | 3 | 4 | 5 |
| g. | I worry about being compared unfavorably to other men. | 1 | 2 | 3 | 4 | 5 |
| h. | I feel I have been too emotional. | 1 | 2 | 3 | 4 | 5 |
| i. | It's hard to think things through coolly and logically. | 1 | 2 | 3 | 4 | 5 |
| o. | I feel as if I am no longer a whole man. | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|---|---|---|---|---|---|---|
| p. | I feel like I've lost part of my manhood. | 1 | 2 | 3 | 4 | 5 |
| q. | I'm not the man I used to be. | 1 | 2 | 3 | 4 | 5 |
| r. | I feel that others think that I'm not the man I used to be. | 1 | 2 | 3 | 4 | 5 |
| s. | I feel weak and small. | 1 | 2 | 3 | 4 | 5 |

## Section Seven: Living With Prostate Cancer

1. How true is each of the following statements for you?

| | | Not at All | A Little Bit | Somewhat | Quite a Bit | Very Much |
|---|---|---|---|---|---|---|
| a. | I am confident that my cancer is under control. | 1 | 2 | 3 | 4 | 5 |
| b. | I worry that my cancer might come back. | 1 | 2 | 3 | 4 | 5 |
| c. | I worry about my cancer spreading. | 1 | 2 | 3 | 4 | 5 |
| d. | I feel that my cancer has given me a better outlook on life. | 1 | 2 | 3 | 4 | 5 |
| e. | I worry keep my thoughts about prostate cancer to myself. | 1 | 2 | 3 | 4 | 5 |
| f. | I feel that coping with cancer has made me a stronger person. | 1 | 2 | 3 | 4 | 5 |
| g. | I wonder whether the treatment I got for prostate cancer really worked. | 1 | 2 | 3 | 4 | 5 |
| h. | It worries me that I can't tell what is going on with my prostate cancer. | 1 | 2 | 3 | 4 | 5 |
| i. | Finding the prostate cancer saved my life. | 1 | 2 | 3 | 4 | 5 |
| j. | I wonder if I would have been better off with a different treatment. | 1 | 2 | 3 | 4 | 5 |
| k. | I sometimes wonder whether it was really worthwhile being treated at all. | 1 | 2 | 3 | 4 | 5 |
| l. | I sometimes feel the treatment I had was the wrong one for me. | 1 | 2 | 3 | 4 | 5 |
| m. | I had all the information I needed when a treatment was chosen for my prostate cancer. | 1 | 2 | 3 | 4 | 5 |

1. How true is each of the following statements for you?

| | | Not at All | A Little Bit | Somewhat | Quite a Bit | Very Much |
|---|---|---|---|---|---|---|
| n. | My doctors told me the whole story about the effects of the treatments. | 1 | 2 | 3 | 4 | 5 |
| o. | I wish I had chosen a more aggressive treatment for my prostate cancer. | 1 | 2 | 3 | 4 | 5 |
| p. | I knew the right questions to ask my doctor. | 1 | 2 | 3 | 4 | 5 |
| q. | I had enough time to make a decision about my treatment. | 1 | 2 | 3 | 4 | 5 |
| r. | If I had it to do over, I would choose some other treatment. | 1 | 2 | 3 | 4 | 5 |
| s. | I am satisfied with the choices I made in treating my prostate cancer. | 1 | 2 | 3 | 4 | 5 |
| t. | I sometimes wish I could change my mind about the kind of treatment I chose for my prostate cancer. | 1 | 2 | 3 | 4 | 5 |
| u. | People in my life don't understand what it's like to have prostate cancer. | 1 | 2 | 3 | 4 | 5 |
| v. | People in my life have been very supportive since I was diagnosed with prostate cancer. | 1 | 2 | 3 | 4 | 5 |

2. Overall, how satisfied are you with the care you have received for your prostate cancer?

| Not at all | A little bit | Somewhat | Quite a bit | Very much |
|---|---|---|---|---|
| **1** | **2** | **3** | **4** | **5** |

3. Overall, how satisfied are you with the way things have turned out since you found out you had prostate cancer?

| Not at all | A little bit | Somewhat | Quite a bit | Very much |
|---|---|---|---|---|
| **1** | **2** | **3** | **4** | **5** |

## Section Eight: General Attitudes

1. How true is each of the following statements for you?

| | | Not at All | A Little Bit | Somewhat | Quite a Bit | Very Much |
|---|---|---|---|---|---|---|
| a. | When a man is feeling a little pain he should try not to let it show very much. | 1 | 2 | 3 | 4 | 5 |
| b. | A man always deserves the respect of his wife and children. | 1 | 2 | 3 | 4 | 5 |
| c. | It is essential for a man to have the respect and admiration of everyone who knows him. | 1 | 2 | 3 | 4 | 5 |
| d. | It bothers me when a man does something that I consider feminine. | 1 | 2 | 3 | 4 | 5 |
| e. | In an emergency a man should be able to take charge. | 1 | 2 | 3 | 4 | 5 |
| f. | Lack of erection will always spoil sex for a man. | 1 | 2 | 3 | 4 | 5 |
| g. | A man should never back down in the face of trouble. | 1 | 2 | 3 | 4 | 5 |
| h. | I think a man should try to become physically tough, even if he's not big. | 1 | 2 | 3 | 4 | 5 |
| i. | I admire a man who is totally sure of himself. | 1 | 2 | 3 | 4 | 5 |
| j. | A man should always think everything out coolly and logically, and have rational reasons for everything he does. | 1 | 2 | 3 | 4 | 5 |
| k. | A man should never go to other people for help if he can manage things himself. | 1 | 2 | 3 | 4 | 5 |
| l. | A man will lose respect if he talks about his problems. | 1 | 2 | 3 | 4 | 5 |
| m. | Men are always ready for sex. | 1 | 2 | 3 | 4 | 5 |

## Section Nine: Health Behaviors

1. How often do you…

| | Never / Rarely | Sometimes | Regularly |
|---|---|---|---|
| a. Read articles or buy literature in order to learn more about ways to protect your health? | 1 | 2 | 3 |
| b. Watch or listen to programs on the TV or radio to learn more about protecting your health? | 1 | 2 | 3 |
| c. Visit web sites on the internet to learn more about your health? | 1 | 2 | 3 |
| c. Exchange information with your friends about ways to keep your health at its best? | 1 | 2 | 3 |
| d. Perform self-examinations or check over parts of your body in order to check for physical changes that might require medical attention? | 1 | 2 | 3 |
| e. Attend prostate cancer support groups? | 1 | 2 | 3 |

2. During the **past 4 weeks**, how much of the time did you...

| | | All of the Time | Most of the Time | A Good Bit of the Time | Some of the Time | None of the Time |
|---|---|---|---|---|---|---|
| a. | Think about how your body feels? | 1 | 2 | 3 | 4 | 5 |
| b. | Try to figure out how your body works? | 1 | 2 | 3 | 4 | 5 |
| c. | Notice changes in how your body feels? | 1 | 2 | 3 | 4 | 5 |
| d. | Wonder why your body feels the way it does? | 1 | 2 | 3 | 4 | 5 |

## Section Ten: Your General Health

**The questions in this section pertain to your health in general, and how any health issues you may have affect your daily life.**

1. In general, would you say your health is:

| Excellent | Very Good | Good | Fair | Poor |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

The following items are about activities you might do during a typical day.

| 2. | Does **your health now limit you** in these activities? If so, how much? | Yes, Limited a Lot | Yes, Limited a Little | No, Not Limited at All |
|---|---|---|---|---|
| a. | Moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf | 1 | 2 | 3 |
| b. | Climbing several flights of stairs | 1 | 2 | 3 |

3. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

| | | Yes | No |
|---|---|---|---|
| a. | Accomplished less than you would like | 1 | 2 |
| b. | Were limited in the kind of work or other activities | 1 | 2 |
| c. | Cut down the amount of time you spent on work or other activities | 1 | 2 |

| | | | |
|---|---|---|---|
| d. | Had difficulty performing the work or other activities (for example, it took extra effort) | 1 | 2 |

4. **During the past 4 weeks,** have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

| | | Yes | No |
|---|---|---|---|
| a. | Accomplished less than you would like | 1 | 2 |
| b. | Didn't do work or other activities as carefully as usual | 1 | 2 |
| c. | Cut down the amount of time you spent on work or other activities | 1 | 2 |

5. **During the past 4 weeks,** how much did pain interfere with your normal work (including both work outside the home and housework)?

| Not at all | A little bit | Somewhat | Quite a bit | Very much |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one best answer that comes closest to the way you have been feeling.

| 6. **During the past 4 weeks,** how much of the time… | **All of the Time** | **Most of the Time** | **A Good Bit of the Time** | **Some of the Time** | **A Little of the Time** | **None of the Time** |
|---|---|---|---|---|---|---|
| a. Have you felt calm and peaceful? | **1** | **2** | **3** | **4** | **5** | **6** |
| b. Did you have a lot of energy? | **1** | **2** | **3** | **4** | **5** | **6** |
| c. Have you felt downhearted and blue? | **1** | **2** | **3** | **4** | **5** | **6** |
| d. Did you feel full of pep? | **1** | **2** | **3** | **4** | **5** | **6** |
| e. Have you been a very nervous person? | **1** | **2** | **3** | **4** | **5** | **6** |
| f. Have you felt so down in the dumps nothing could cheer you up? | **1** | **2** | **3** | **4** | **5** | **6** |
| g. Did you feel worn out? | **1** | **2** | **3** | **4** | **5** | **6** |
| h. Have you been a happy person? | **1** | **2** | **3** | **4** | **5** | **6** |
| i. Did you ever feel tired? | **1** | **2** | **3** | **4** | **5** | **6** |

7. **During the past 4 weeks,** how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

| All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|
| **1** | **2** | **3** | **4** | **5** |

8. **Compared to one year ago,** how would you rate your health in general now?

| Much better now | Somewhat better now | About the same | Somewhat worse now | Much worse now |
|---|---|---|---|---|
| **1** | **2** | **3** | **4** | **5** |

12. How TRUE or FALSE is each of the following statements for you?

| | | Definitely True | Mostly True | Don't Know | Mostly False | Definitely False |
|---|---|---|---|---|---|---|
| a. | I think my health will be worse in the future than it is now. | 1 | 2 | 3 | 4 | 5 |
| b. | In the future, I expect to have better health than other people I know. | 1 | 2 | 3 | 4 | 5 |
| c. | I expect to have a very healthy life. | 1 | 2 | 3 | 4 | 5 |
| d. | I expect my health to get worse. | 1 | 2 | 3 | 4 | 5 |
| e. | My future will be unhealthy. | 1 | 2 | 3 | 4 | 5 |
| j. | Good health is in my future. | 1 | 2 | 3 | 4 | 5 |

14. **During the past 4 weeks,** how much have you felt...

| | | Not at All | A Little Bit | Somewhat | Quite a Bit | Very Much |
|---|---|---|---|---|---|---|
| a. | My health could take a turn for the worse at any time. | 1 | 2 | 3 | 4 | 5 |
| b. | I doubt that cancer will ever be a big problem for me. | 1 | 2 | 3 | 4 | 5 |
| c. | I sometimes worry about dying before my time. | 1 | 2 | 3 | 4 | 5 |
| d. | I worry about what my doctor will find next. | 1 | 2 | 3 | 4 | 5 |
| e. | I worry that changes in my medical condition will not be detected early. | 1 | 2 | 3 | 4 | 5 |
| f. | I am uneasy about the present state of my health. | 1 | 2 | 3 | 4 | 5 |
| g. | It is hard to make sense of what I am told about my health. | 1 | 2 | 3 | 4 | 5 |

15. How true has each of the following statements been for you **during the past 4 weeks**?

| | | Not at All | A Little Bit | Somewhat | Quite a Bit | Very Much |
|---|---|---|---|---|---|---|
| a. | I keep close track of my PSA. | 1 | 2 | 3 | 4 | 5 |
| b. | I live in fear that my PSA will rise. | 1 | 2 | 3 | 4 | 5 |
| c. | I am confused by what PSA really means. | 1 | 2 | 3 | 4 | 5 |
| d. | Knowing my PSA level is comforting to me. | 1 | 2 | 3 | 4 | 5 |

## Section Eleven: Personal Background Information

1. Which category best describes your race / ethnic background?

| White | Black / African-American | Hispanic / Latino | Asian / Pacific Islander | Aleutian, Eskimo, or American Indian | Other *Specify*: _____ |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 |

2. What is your current marital status? (Circle one number.)

| Married | Widowed | Separated | Divorced | Never married |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

3. How would you describe your current work or retirement situation? (Circle one number.)

| Working at a paying job full or part time | Retired, not working at all | Retired, but working part or full time | Laid off or unemployed | Other *Specify*:_____ |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

The following list includes events that may occur in anyone's life from time to time. Each one may have a good effect, a bad effect or no effect on a person's life. Think back over the **past 12 months** of your life.

4. Over the **past 12 months**, have any of the following events occurred in your life?

| | Yes | No |
|---|---|---|
| a. Someone close to you had a serious illness or injury. | 1 | 2 |
| b. You had a financial crisis. | 1 | 2 |
| c. Someone close to you died. | 1 | 2 |
| d. You resigned or retired from work. | 1 | 2 |

*Thank you for completing The Prostate Cancer Quality of Life Questionnaire.*

Have you…

- Reviewed and circled all the answers? ☐
- Signed the informed consent form on the second page? ☐

Enclose both the survey AND the informed consent form in the self-addressed stamped envelope we have provided for you and drop in any mailbox.

If you should have any questions, please call Kristen Solemina at (781) 687-3255.